

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



Conference venue: KKL Lucerne

THE BPA GOES INTERNATIONAL

This year the International Congress of Porphyrins and Porphyrrias is being held in Lucerne, Switzerland, between the 15 and 18 May. A number of the BPA's committee members will be attending the main 'Scientific Conference' and we will aim to provide feedback from this at our June Open Day at Kings. In addition, on Saturday 18 May, there will be an International Patient Conference, similar to the one in April 2011, in Cardiff. This event was very well received. We understand that 11 people from the UK are attending the Patient Conference.

This will provide an excellent opportunity to hear about new developments in the world of porphyria, whilst also enjoying talks from many international porphyria experts and from patients from across the world.

The BPA recently also joined with porphyria patient organisations in other countries, to create pages for porphyria on the Rare Connect website. Rare Connect is

an international organisation linking rare disease organisations (partly funded by the European Union). The new website is www.rareconnect.org/en/community/porphyria.

We have high hopes that this new initiative will bridge the current gaps in knowledge that are often experienced by porphyria patients and their families.

The website is monitored by a number of expert moderators from across the world (Sue Burrell, one of our trustees and an expert AIP patient, is a moderator of the website). This community is working to collate international experiences so that their members can learn more about other porphyria patient's experiences. It provides opportunities to meet (in a forum/blog style) with other porphyria members and learn from their experiences.

The BPA are happily supporting this initiative and we look forward to seeing how this online community will develop in the future.

NEWSFLASH

We have a new telephone **HELPLINE** number – **0300 30 200 30**.

Calls to 03 numbers cost no more than a national rate call to an 01 or 02 number and count towards any inclusive minutes in the same way as 01 and 02 calls. These rules apply to calls from any type of line, including mobile, BT, other fixed line or payphone.

The new helpline number will now be answered by Liz Gill.

Our email helpline remains the same: helpline@porphyria.org.uk and is run by Alan Molyneux.

LIANNE'S STORY – HEREDITARY COPROPORPHYRIA (HCP)

“DUE TO THE NERVE DAMAGE FROM SO MANY ATTACKS IT TOOK UNTIL 2003 BEFORE MY NERVE CONDUCTION TESTS SHOWED COMPLETE RECOVERY.”

I'm 37 and was diagnosed with HCP at the age of 21. The first acute attack was in 1996; I was admitted to hospital with acute abdominal pains, but no apparent cause was found so I was sent home. The pains worsened, accompanied by nausea, constipation and convulsions. At this point I had severe muscle weakness, difficulty walking, and my speech began to slur and stutter. I was repeatedly admitted and discharged with nothing diagnosed. My speech and mobility continued to worsen, and I was eventually admitted to hospital with a suspected brain tumour. CT scans revealed this was not the case, but I was now completely paralysed and could only stutter a few words. Despite many tests, I was told it must be stress related: I was a student and holding down several part-time jobs. They stopped the medication I was taking (mefenamic acid for bad period pains) and over the coming weeks my speech returned and, with physio, I learnt to walk again.

I returned to university, although my health had its ups and down. But if the abdominal pains got bad and I had convulsions I would suffer at home. Nearly 7 months later the hospital asked me to come in as some mislaid blood tests had been found from when I was admitted initially. I was asked if anyone in my family had Porphyria. I'd never heard of it. My urine was sent to Cardiff for analysis and after a while I was told it was Hereditary Coproporphyrria. I remember the relief at being told what it was and everything began to make sense. I was also told that mefenamic acid was the trigger.

Due to the nerve damage from so many attacks it took until 2003 before my nerve conduction tests showed complete recovery. My porphyria settled down for a few years and only a handful of hospital admissions took place between 2004 and 2011, for which I was treated with glucose drips and sent home.

During recent years I had more attacks (in line with my

menstrual cycle), but having a young family I would not go into hospital. I'd meet with Dr Badminton a few times a year and he advised my GP to look into other possible health problems that could be the trigger – I have always stuck to my safe list of drugs and have avoided alcohol. In January 2011, I was found to have a fibroid (1.5cm) and this could be the cause. It was recommended I have hormone treatment, but my GP did not inform me of this, so I continued to have attacks. By January 2012 they had got so bad that I agreed to stay in hospital. Tests revealed my fibroid was now 10cm (and growing rapidly) and I also had endometriosis; I would need a total hysterectomy including removing my ovaries.

I have had an acute attack every month in 2012. In February my haematologist got involved and for the first time I had haem arginate treatment. I have had a course of treatments each month via a central line and it really

makes a difference. In April I had surgery to remove my womb and ovaries, but am still having acute attacks and have nerve damage again. There has been mention of a portacath to allow me to have weekly haem arginate, as a preventative measure, rather than waiting for attacks to start. I feel very lucky to have such a good team of haematologists and I'm not afraid to go into hospital at the first sign of an attack. I have a six-year-old daughter who has inherited HCP, but I hope and pray that she never has an acute attack as my twin sister, elder brother and mother (all with HCP) have been fortunate never to have suffered.

Knowledge is key, and more often than not we, as patients, are the first point of reference for information about Porphyria. I always remember to carry a safe list of drugs where ever I go!

An extended version of Lianne's story, and other patient stories are available on our website: www.porphyrria.org.uk.

MEDICALERT® DISCOUNTS

MedicAlert® provides medical identification jewellery for people with hidden medical conditions, allergies or the need to convey important information in an emergency. Situated on the pulse points, our necklaces, watches and bracelets display the international medical symbol to identify your condition in an emergency. This helps medical professionals get you the right treatment quickly, particularly if you are unable to speak.

Your membership of MedicAlert gives you peace of mind that goes far beyond

your bracelet. Your medical conditions will be reviewed by our medically trained staff, who will prioritise the text engraved on your jewellery. A detailed medical record is also held in our secure database, which can be accessed 24/7 by emergency responders. As a leading international charity, you'll benefit from global awareness of MedicAlert emblems, as well as our education programme with emergency responders. Our emergency phone line is manned 365 days a year, and supports translation in over 100 languages – providing that

extra reassurance if you are travelling.

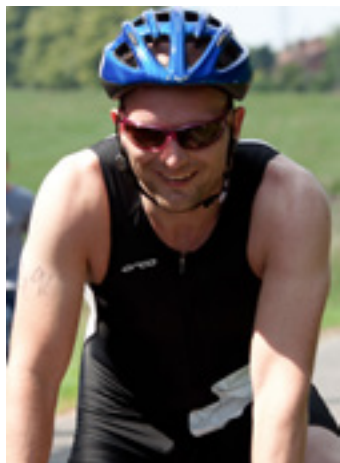
MedicAlert and the BPA have joined forces to help raise the importance of wearing medical ID for people who have Porphyria, enabling fast condition identification and appropriate treatment in an emergency. By joining today and quoting 'BPA' you will receive £5 off your first piece of jewellery when joining MedicAlert on Annual Membership paid by Direct Debit (£27.50 per year). Call MedicAlert on 0800 581 420, or complete your order online at www.medicalert.org.uk.



RIDE LONDON-SURREY 100 – AUGUST 2013

The BPA would like to congratulate Ian Burrell and Glenn Blake for successfully obtaining the two BPA charity places for the 'Ride London-Surrey 100' which will be held in London on Sunday 4 August 2013. Ian and Glenn are currently training hard, but they are also very excited to be part of this inaugural event. They will train together over the coming months and they will then complete the 100 mile bike ride within the day – they are hoping for a time of around 7 hours!

The BPA wish Ian and Glenn the best of luck for the event, and we would like to thank them for all of their hard work and support – 'Go Norwich Boys!' Please support them by sponsoring their event – or you can just see how they are progressing – by visiting their JustGiving webpage: www.justgiving.com/thenorwichboys.



GETTING INSURANCE

Getting life insurance or travel insurance can be a tricky issue for people with a pre-existing medical condition, such as porphyria.

Members often ask us who might cover them and the answer is that this depends on each individual case. Some members have had success with Tesco, American Express, Insure and Go and Freedom Insurance.

Recently, however, we have also learned of two useful price comparison websites that deal with travel cover for those with pre-existing conditions. Using a comparison tool, you are able to compare travel insurance companies that cover medical conditions as part of their policies. Please see: www.moneysupermarket.com/travel-insurance/pre-existing-medical-conditions/ and www.comparethemarket.com/travel-insurance/with-medical-conditions/.

Once you have answered all the relevant questions there are a number of potential outcomes; companies may:

- offer a standard travel insurance policy
- exclude medical cover for certain pre-existing conditions
- offer the insurance but at a higher price

- refuse to insure you or impose certain restrictions, exclusions, special terms or excess payments.

These particular price comparison websites recognise porphyria and also AIP, CEP, EPP and HCP individually.

Life insurance is occasionally more difficult; you may need to appeal an initial refusal. If so, you will need to gather all the information relevant to your individual case. Sometimes a letter from your doctor will help.

REMEMBER: Failure to declare a medical condition to an insurer could result in any claim being rejected. It may be tempting to withhold certain information in order to obtain a cheaper premium, but in the event of a claim, the insurance company can access your medical records.



MASSIVE THANK YOU

The BPA would like to say a huge thank you to Sylvia King and her friends and family, especially those in the Keynsham area. Over an extended period and through various fundraising events they have managed to raise an enormous £2476.17 for the BPA. THANK YOU and well done.

MANY THANKS TO KAREN HARRIS

The BPA would like to formally thank Karen for her many years of dedicated support to the BPA. Karen was not only instrumental in establishing the charity, but she also single-handedly answered the helpline for many years. In addition, over the years Karen has raised considerable funds for the BPA through various events, including coffee/open

mornings, sponsored walks and other events such as her 2013 'South Downs Trekathon' in which Karen and three of her friends/family (Sian Harris, Wendy Hicks and Candy Elsworth) have committed to 'trek' 26 miles in one day – they have already raised £276.00 and are well on target to raise their estimated £500.00 by the time of the event in May 2013.

We wish Karen and the girls the best of luck and thank them in advance for all of the hard work that goes into an event like this, from the planning, the training, through to the fundraising and the actual event itself – 'go girls!' If you would like to sponsor Karen, you can do so via her JustGiving page: www.justgiving.com/Pilatesgirls.



HELPLINE

0300 30 200 30

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

web: www.porphyrria.org.uk
email: helpline@porphyrria.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: Jacqueline Binns
Patrons: Prof. Timothy Cox, Prof. George Elder, Dr. Mike Badminton
Prof. Felicity Stewart

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BPA EVENTS IN 2013

Open Day at King's College Hospital, London, on Saturday 8 June, 10 am to 4 pm

Refreshments at 10 – 10.30 am will be followed by various clinical talks from Dr Marsden, Dr Rees, Dr Sarkany and Simon Guppy (Kings' new Clinical Nurse Specialist). In addition, there will be a patient testimonial, a question and answer session and a tour of the labs. It is FREE to attend and includes lunch and refreshments.

BPA Autumn Conference & AGM, Dundee, on Saturday 21 September 2013 (afternoon).

This is still being planned with Dr Dawe and his team. It will include a very brief AGM, and talks by experts and patients.

Please contact us if you would like to attend either event, so we can send further information.

WELSH MEDICINES INFORMATION CENTRE

A common problem with the acute porphyrias (AIP, VP, HCP or ALA-D deficiency porphyria) is knowing whether or not a medicine is likely to trigger an acute attack.

The Welsh Medicines Information Centre (WMIC) has created a list of SAFE drugs in common use; available at www.wmic.wales.nhs.uk/porphyria_info.php - simply click on the link to Drugs considered safe in the acute porphyrias.

WMIC also provides a specialist advisory service which allows porphyria

patients, doctors and other healthcare professionals in the UK to check if a particular drug is safe for use. WMIC provides valuable advice for complicated porphyria/drug related issues, such as needing to use an unsafe drug in an emergency. We need to continue to use this service, or it may be lost.

While many drugs are considered suspect a good alternative can almost always be found. They can be contacted by telephone on **029 2074 3877** or **029 2074 2251**, or fax on **029 2074 3879**.

THE 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 www.justgiving.com
 I would like a receipt

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. 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, Rothlea House, 7-8 Quarry Lane, Butterknowle, Bishop Auckland, County Durham, DL13 5LL
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:
Sort code: 20-43-63 Account No: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