



Looking back over the past 10 years

The British Porphyria Association is celebrating its 10th birthday this year. As I have been involved with the association from its inception, I thought I would look at what we have achieved in that time.

A small group of us were brought together, in London, with Professor Timothy Peters, Professor Timothy Cox, Professor George Elder, Lesley Green from Climb and Orphan Europe. We were invited to form a patients association as there was nothing available to patients and their families.

We set about organising our first meetings to discuss how we could do this, as we came from various parts of the UK, and most of us had full time jobs to do.

After several meetings we decided to look at ways to raise funds, and also how to register ourselves as a charity. Each member of the 'committee' agreed to do certain tasks. Gradually we put together our aims and mission statement, raised funds from family and friends, doing quiz nights, discos, and sponsored events. It was a huge struggle and sometimes meetings had to be cancelled due to ill health.

Over the years we have taken turns to attend medical and research meetings, reporting back through the newsletter. Published twice a year, we all take turns writing items of news, and then the job of addressing, stamping and posting them out. Some of us have 'roped the children in' to help with stuffing envelopes, on the promise of extra pocket money!

Committee members have come and gone. To mention just a few: John and Carol Smith (our first treasurers) gave many hours to BPA and raised hundreds of pounds: Deborah Holdsworth

(our original secretary) took minutes at our meetings, typed them and distributed them: Pam Spencer and her family business Clark-Drain gave us the use of their conference rooms for meetings and have covered the cost of several of our newsletters: Leigh Drake was active on the committee for 3 years (2003-2006), and was correspondence secretary for 2004-2005 (She left to get married.): Linda Everest did not have a particular role, but helped out in many ways.

On our current committee, John Chamberlayne (Chairman) set up and manages our web site. Kirstine Chamberlayne and Liz Gill wrote our educational leaflets, to give to new patients, hospitals, doctors, nurses and anyone seeking to learn more about the porphyrias. Liz Gill also helps our "acute" members who, like her, have continuing symptoms, by listening and offering advice based on her own experiences. Anne Newton looked after our accounts for many years, and recently handed the job over to Alan Molyneux.

Sarah Pepperdine (secretary) answers emails and letters, and also gives help to other EPP patients and their families. Sandra McNab, who joined recently, advises on PCT. She lives in Scotland and is trying to set up a local group.

We now have monthly MSN meetings, to discuss ongoing projects, open meetings, the newsletter, correspondence and who does what. We also have two face-to-face committee meetings each year.

Thanks to on-going fund raising by members, we have given funds to various research projects, investigating problems to do with EPP, AIP and CEP in particular. We have also been able to help some families with special needs.

We can direct members to specialist centres, where they see doctors who understand the porphyrias and can help them maintain a healthy lifestyle. We have a good relationship with our medical and research advisors and many have given talks to our AGM (usually held in October) or our June meeting, held on or near National Porphyria Awareness Day on 1st June. Meetings are held in different venues around the country to give as many members as possible the chance to come and meet others in the same situation.

So, what of the future?

We hope to continue to grow and raise awareness of porphyria. However, we can't do that without YOUR help.

Can you raise some funds for us this year?

We have lots of ideas (some are good fun). We always need new committee members - an extra pair of hands or fresh ideas. You do not have to attend every meeting. We are all volunteers, friendly and with a great sense of humour.

Why not call us to discuss how you can help? Just ring 01474 369 231

(if I can't answer, leave your name and a phone number and I will call you back)



**Karen Harris,
Helpline
Co-ordinator
and former
Chairman.**



The Welsh Medicines Information Centre (WMIC)

One of the recurrent problems with **the acute porphyrias (AIP, VP, HCP or ADP)** is knowing whether or not a medicine is likely to trigger an acute attack. (Those with EPP, PCT or CEP do not have to worry.)

The Welsh Medicines Information Centre (WMIC) has created a comprehensive list of **SAFE** drugs for use in the acute porphyrias. You are advised that you and your doctor stick to this list unless there are very good reasons why you shouldn't. This list is available at www.wmic.wales.nhs.uk/porphyria_info.php (and via the BPA web-site) - simply click on the link to *Drugs considered safe in the acute porphyrias*.

In addition, WMIC provides a specialist advisory service which allows porphyria patients, doctors and other healthcare professionals in the UK to check whether a particular drug is safe for use. WMIC provides valuable advice for complicated porphyria/drug related issues. The contact centre will need to know the patient's name, age and sex, the type of porphyria they suffer from, whether it is active and what they are being treated for.

While there are many drugs which are considered suspect, a good alternative can almost always be found – please ask WMIC – they are there to help. The centre contact telephone number is **029 2074 3877** and the fax number is **029 2074 3879**.

Please do make use of them. They are very friendly, and will only continue to be funded if they are used!

Hilary's story

Hilary had suffered from AIP since she was 17, and went for regular check-ups every 6 weeks. At the age of 45, in November 2006, she was told she was anaemic and needed iron injections.

In February 2007 she collapsed at home, and it was 4 hours before she regained consciousness. In hospital, after weeks of tests and feeling better, Hilary wanted to go home but a doctor who dealt with diabetes wanted to run further tests. After 6 months in hospital, Hilary started to lose the use of her arms and legs, as well as developing bed sores.

Her condition deteriorated and she was rushed to Liverpool Royal Hospital, where she had to be fed by a naso-gastric tube for 39 weeks. Her partner, Neil, contacted Kings College Hospital, who advised him that Hilary should not have had the 7 iron injections, but should have had tablets. [*Injections of iron increase the demand for haem too rapidly, which causes an acute attack. Iron from tablets is absorbed much more slowly, so is less likely to cause an attack.*]

After a year in hospital, Hilary went home with a Zimmer frame, with carers and her partner to look after her. Within 8 days, she had returned to hospital, after being given tablets for a water infection by her GP. She was in for a further 2 months, fed by naso-gastric tube plus some food that was brought in for her.

Hilary was later sent to a rehabilitation centre to learn to walk and use her hands again. After 4 months, she is still in a wheelchair but is now trying to rebuild her life after 19 months in hospital.

Contraception in the acute porphyrias

Contraception is often a tricky subject for those with one of the acute porphyrias (AIP, VP, HCP or ALA-D deficiency porphyria).

Oral contraceptive pills are listed on the **UNSAFE** drugs list as they are known to provoke attacks of acute porphyria, either alone or by interacting with other factors. The pill, particularly the progestogen element, can trigger acute attacks; however, there are numerous reported cases of women who have inherited one of the acute porphyrias taking the pill without adverse effects. Unfortunately, there is no way of knowing how a woman with porphyria will react to the pill, it is at best a risky option and should never be undertaken lightly. The general advice is to avoid the pill and other hormonal methods of contraception. In particular, injectable and implanted hormonal preparations should never be used as they cannot be removed if an attack starts.

So, now we know what to avoid, what are the alternatives?

The simplest solution is to use a barrier method of contraception, eg the male or female condom, the diaphragm or the cervical cap. Physical barrier methods can offer effective and acceptable contraception to individuals who use them consistently and correctly. It is also important to remember that the condom is the only method to adequately protect against sexually transmitted infections (STIs) and HIV.

Other contraceptive options include inter-uterine devices (IUD) such as the copper coil or the Mirena coil. The Mirena coil contains a progestogen that has a local action within the uterus and only enters the bloodstream in very small amounts. Experience to date suggests that this sort of device carries a very low risk of provoking an acute attack although, if the porphyria patient has already suffered an attack, it may be wise to choose the copper coil which is hormone free. It is important to remember that IUDs are not suitable for all women (they can cause heavy periods and stomach cramps) and some young women may have problems convincing their doctor that it is a good idea.

In terms of emergency contraception, 'the morning after pill' contains high doses of progestogen which are dangerous in porphyria – this is not a solution! For emergency contraception insertion of an inter-uterine device is the safe alternative.

Overall, it is important that you take responsible steps to ensure that you have a solution which suits your lifestyle. Talk to your GP or family planning clinic about appropriate options.

NEWS FLASH • NEWS FLASH

Swine Flu

Our medical experts have confirmed
that the drugs used for influenza
- oseltamivir (Tamiflu) and zanamivir (Relenza)
are considered SAFE for use in acute porphyria

“Genetics for Patients” project now recruiting

Dr Marion McAlister, from The University of Manchester, is researching new ways of measuring whether people from families affected by genetic conditions may benefit from attending a genetics clinic. Marion is developing a questionnaire to examine patients' thoughts, feelings and attitudes about the family condition, that could be a useful tool to improve genetics services.



Marion is looking for people aged 17 years and older from families affected by genetic conditions to help, by completing an early version of the questionnaire.

If you would like to help, please go online to www.geneticsforpatients.org.uk
using PIN number 1144 to complete the questionnaire online,
or contact Marion to obtain a paper questionnaire.
(Tel: 0161 276 8979, E-mail: marion.mcallister@manchester.ac.uk)

Report on Questionnaire

Our Chairman writes:

In the summer of 2006 many of our members completed a questionnaire we sent them. I summarised the results the following year, and presented them to porphyria medical experts, and at BPA meetings. I have finally completed a report of the results, which we have sent out to all those who answered the questionnaire. If anyone else would like a copy, it can be downloaded from our web-site, or we can send you a copy.

UPDATE on AIP study

We have recently had an update from Dr Helen Murphy, who is leading research into the varying effects of AIP. As with all studies, a major part is obtaining ethical approval to approach patients all over the country, to do the research. Helen has just completed this stage, and is now starting to contact patients to arrange the interviews and blood samples.

If you have already contacted her, you should be hearing from her soon. If you have not done so, but would like to take part, do contact her on 0151 802 5031 or 5008, email: lwft.AIPstudy@nhs.net or at: Dept of Clinical Genetics, Alder Hey Hospital, Eaton Road, Liverpool, L12 2AP.



Autumn Conference and AGM 2009

We are having a half-day conference in London, on Saturday 3rd October.

It will start at 2.00pm. and be at King's College Hospital, Denmark Hill, London SE5 9RS (in the Bill Whimster Suite).

After a short AGM, we hope to have talks by Dr Bob Sarkany, Dr Joanne Marsden and Dr David Rees.

All have spoken before at BPA events, and are well worth hearing. Dr Bob Sarkany is a dermatologist, who specialises in EPP and other skin porphyrias. Dr David Rees specialises in acute porphyrias, and Dr Joanne Marsden heads the lab. The day will include a question and answer session.

We will provide refreshments, and you will be able to talk to other porphyria patients, to the committee, and to the medical experts.



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.porphyrria.org.uk

E-mail: 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

Treasurer: Alan Molyneux

Secretary: Sarah Pepperrine

Patrons: Prof. Timothy Cox, Prof. George Elder
Dr. Mike Badminton

View points and opinions contained in this newsletter are reproduced in good faith and do not necessarily reflect the judgement of the British Porphyria Association or its patrons.

Our first meetings in Scotland

In June we are having our first main meeting in Scotland, at Ninewells Hospital in Dundee, on Saturday 13th June; from 10.30am to 4pm. It will be in the Department of Photobiology & Dermatology, on level 8 above the polyclinics.

We will have talks by Dr Dawe, a porphyria specialist at Ninewells, and Dr Woods, who is an expert at porphyria testing. As well as the talks, we will have a question and answer session, and then a tour of the labs where porphyria tests are done for Scotland. The talks will include both the acute porphyrias, and skin porphyrias.

It should be well worth attending. Ninewells Hospital does the biochemical testing for porphyria for the whole of Scotland. **We do not have many members in Scotland; so if you live there - or the north of England - please come along and support it.**

Our Scottish committee representative, Sandra McNab, is also trying to get together a meeting of BPA members, mainly from the greater Glasgow area.

Skin Porphyrias

Dundee cream is recommended for covering up in the sun. It needs to be applied 1 hour before exposure and renewed after 2 hours. One teaspoonful is needed on each area – face, neck, ears, front of trunk, limb, etc.

One of the talks last year recommended the web site sun1.awardspace.com for those with skin problems.

Also our Secretary, Sarah, is looking to set up an group of EPP sufferers to exchange stories, helpful hints and tips etc.

Please keep a look out on the BPA website for more information! www.porphyrria.org.uk



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 £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 opposite)

I have set up a Standing Order on-line*

I enclose a cheque made payable to the 'British Porphyria Association' for £ _____

I have made a payment on-line*

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, 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.

Standing Order BRITISH PORPHYRIA ASSOCIATION

Please send this form to: The Treasurer, British Porphyria Association, 599 Bolton Road, Aspull, Wigan, Lancs, WN2 1PZ.

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 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.)

DATE: _____ SIGNATURE: _____