# 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.**

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|---|---|
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*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.*

# UPDATE: Photo Competition for calendar


As announced in the last newsletter, we are holding a competition for photos for a calendar we are planning to produce for next year. We haven't had a great number of entries (apart from snow ones! ), so do send yours in.

The subject is nature or weather.

The deadline has been changed to the end of June.

You may submit up to 6 photos along with your name, age and contact details.

Send them as high quality prints, or a disk to Karen Harris, 14 Mollison Rise, Gravesend, Kent. DA12 4QJ; or email high quality jpegs to photos@porphyria.org.uk

# Open day in Cambridge

This year, we are holding our open day in Cambridge. It will be held on Saturday 12th June at the Sidney Sussex College in Cambridge (CB2 3HU).

Professor Cox, from Addenbrooke's Hospital is our host. There will be further talks by other porphyria experts, as well as a question and answer session.

It is a good chance to meet experts in porphyria and other sufferers and their families.

The presentations will begin at 12pm and the day is expected to finish by 4pm. Tea and coffee will be served from 11.30.

Please let us know if you need further directions.

## 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, 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 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:



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The British Porphyria Association newsletter

Registered Charity No.1089609

ISSUE 19 • DECEMBER 2009

Lifestyle montage here

# Living with EPP

**My name is Beth Ward and I have suffered with EPP for my whole life. However it wasn't until I came to my first BPA meeting in Leeds in June 2008 (aged 34) that I met others who also suffer from EPP. Like many who suffer from any type of Porphyria I have always felt quite isolated and felt that no-one (even close family) really knew what this meant.**

The reason why I am writing this article is that I want you all to feel that you are not alone and also that it is not all doom and gloom having Porphyria. I have already met some nice people through the BPA!

I was born and bred in Yorkshire and brought up with two older brothers. It wasn't until I was about 3-4 years old after lots of nagging at Doctors that my parents were eventually put in touch with a consultant who diagnosed me with EPP.

I guess like many young people with EPP I felt conscious of wearing long sleeve clothes or having to put up an umbrella or even stay inside. What I can say is that suncreams and UV clothing have come a long way since I was a child. I remember being about 10 years old and having to wear this bright pink zinc cream (like cricketers wear) on my face and hands. It looked like I had pink cement put on my face!!

However my family didn't wrap me up in cotton wool and keep me indoors all the time. Instead we went on holidays to Europe most years. Although this sounds harsh it taught me how to enjoy travelling overseas but also how to avoid the sun at the same time. Therefore I swam in the sea at 5pm at night when everyone else was leaving the beach and made more of the evenings.

This gave me a keen interest in travel and for a few years I worked for the British Tourist Authority in London promoting Britain overseas. This meant I had to travel to the USA and Europe for work. I just had to work things out my way for doing exhibitions outside. They were always in the shady areas! I have continued to work on outdoor events such as Food & Drink Festivals and the likes in my present role as Halifax Town Centre Manager. Fellow EPP sufferers must think I am mad!!

In order to help me with EPP and the outdoor events I do I have decided this year to undertake the desensitivity treatment to allow me to hopefully stay in the sun longer this Summer. I talked to some fellow sufferers at the BPA meeting in London in October last year and they recommended the treatment. However I said to Dr Sarkany that I would be unable to get to London or Dundee (where I knew they offered the treatment) for several weeks in the Spring due to work commitments. Dr Sarkany mentioned that I could be treated at my local hospital and if they didn't know how to undertake the treatment he would send them information. As promised he did.

As I am writing this, I have just had my 5th session of treatment on what I call a vertical sunbed and at each session the time and intensity has increased. I am now up to approx 9 seconds. My family laugh when I say I've been to hospital for 9 seconds of treatment as it takes me longer to get changed! – it was 4 seconds initially!! I will continue to go for the next 7 weeks and hopefully this will help me in the Summer.

I wanted to help other Porphyria sufferers and hence joined the BPA Committee to help with marketing and PR. My first thing I have done is set up a Facebook site group called British Porphyria Association. The reason for this is that I think Porphyria sufferers need a channel to liaise with each other whenever we so desire or need to pick each other's brains about something or even to give us a "pick me up" when we are feeling a little down. All you have to do is write "British Porphyria Association" into the search box on your Facebook site and join the group. On the site there is a list of BPA events, a link through to the website, discussion topics and anyone can put up any questions or ideas. You don't even have to be based in Britain! Join us on Facebook.

By Beth Ward (Email: bethtippey@hotmail.com)

image here?

## New Facebook site

**Please note that we now have a Facebook site – British Porphyria Association.**

**PROFILE NAME HERE**

# Kerry's Story

**My mum became very poorly when she was a teenager, so poorly doctors thought she was going to die. Eventually she was diagnosed through tests as having AIP.**

I as a teenager, myself having suffered many bouts of severe stomach cramps, sickness and muscle pains (sometimes unable to even move my eyes) was also diagnosed as having AIP after being tested on and off for years. It took my brother to be injured in a car accident and a new doctor from a different department (unaware of the possibility of him having AIP) seeing something unusual in his blood to diagnose him also with AIP.

A doctor who was seeing my family decided a few years ago that the results were wrong as we had not returned any positive results for a while. This I found shocking - as you yourself will know, borderline and negative results can be achieved in people with AIP. My mum, having had to go through a hysterectomy and being advised to discontinue her pregnancy with my brother, found this unbelievable.

Myself and my mother went to Glasgow for a second opinion, where the doctor concluded that he could not understand why our Aberdeen doctor, after all these years and us having all tested positive at different times and all having had symptoms of AIP, would be happy for us to take medication that was not acceptable with AIP. Ourselves, with the help of our main doctors practice, ensure all medications are safe with AIP.

My main concern now is for my 3 children and my 2 nieces, as no-one has made any contact about testing them since the genetics doctor at Aberdeen. I mentioned when my daughter was born that I had tested positive for AIP and they contacted the genetics department. They said they will wait and test her when she is older. My sons are 14 and 12 and my daughter now 3.

I myself as well as my mother and brother had blood, urine and stool sampling. We ourselves used to be contacted to be tested regularly, especially myself and my mother but all communication has stopped since we asked for a second opinion. We were told we no longer needed to attend and have been unable to discuss what the opinion of the doctor in Glasgow was. We do continue to have symptoms regularly especially during menstrual time. I receive painkillers from my doctor that just about take the edge off the pain and avoid anything that could cause an attack as much as I can.

*We have given Kerry further advice on testing, for her to pass on to her doctor. If you want advice from the BPA to pass on to your doctor, do contact us.*

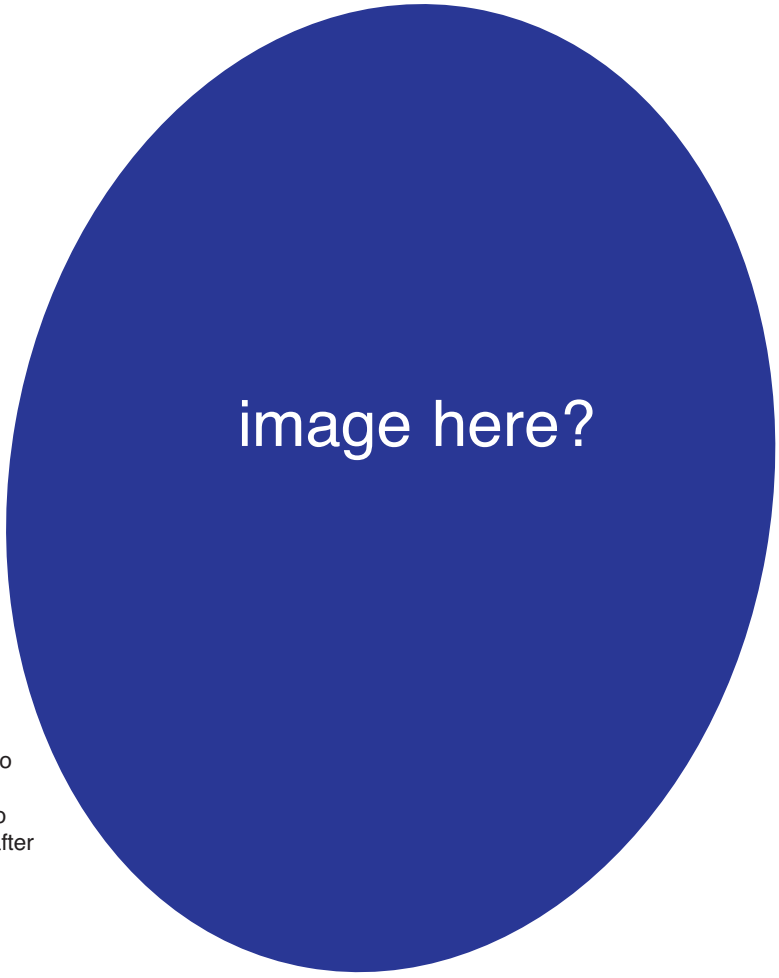
***We would welcome other members stories for future editions of the newsletter.***

# Pregnancy in acute porphyria

Research presented at the Porphyrins and Porphyrias conference in Stockholm included a retrospective study, by British doctors Joanne Marsden and David Rees, on the outcome of pregnancy in patients with acute porphyria.

Although the sample was relatively small (only 15 women), obstetric complications were few and porphyria related complications were also minor. The report also revealed that a couple of women more severely affected by their porphyria were treated with Haem Arginate during pregnancy and this was remarkably well tolerated with no adverse effects being observed on the baby (although this is no guarantee that this is safe, as yet). More research will need to be undertaken to investigate this further.

Overall. this research is optimistic for those diagnosed with an acute porphyria and planning to have children, however, it is vital to be closely monitored by your GP and specialist (beforehand and during pregnancy) should you decide this is something you want to do. Although some patients do have acute symptoms during and after pregnancy, the majority of women with porphyria appear to tolerate pregnancy well.



# Vampires, Werewolves and Madness: the myths of porphyria.

**You're probably wondering what vampires have to do with porphyria.**

Well what are vampires supposed to be like? Don't they drink blood and keep away from light? Isn't that what people with Variegate Porphyria do? This suggestion came from a "scientist" who suggested that porphyrics drank blood to damp down attacks and avoided going out in daylight so they didn't get blistering.

Our daughter had great fun with this idea in hospital, one night when she couldn't sleep. She went to talk to the nurses, and was telling them she was supposed to be a vampire. One nurse told me they had a really good laugh at her antics.

Fun it may be, fact it is not.

The idea that you can drink whole blood to damp down an attack is rubbish. I wish it was really that easy! The so-called scientist had obviously never heard of digestion - probably one of those people who thought biology isn't a science. (They aren't so common these days, thank goodness.)

Haem from blood is used to treat attacks but digestion destroys haem, so swallowing blood is no good at all. It has to be very carefully extracted from donated blood, converted to haem arginate, then given through a vein (like a blood transfusion). 4 small infusions are given, one on each of 4 successive days. It's the best treatment we have for acute attacks. Unfortunately, there are some people who believe that drinking human blood helps them. Our friends in America came across one. With great restraint, they told his wife that he was mentally ill and to seek help.

Generally, Variegate Porphyria doesn't stop you going outside in daylight. Yes, it's as well to use sunscreen and avoid the mid-day sun in summer, but all it takes is a little care. It's our friends with EPP and CEP who have real problems with daylight. I don't suppose they'd be very amused at the idea of someone chasing them around with a sharpened stake. Another fantasy supposedly explained by a porphyria is werewolves, the ones who are supposed to be human in daylight, growing hair and morphing into wolves in moonlight. In this case, the porphyria is PCT since it can cause excess hair growth, mostly on the cheeks and forehead.

Have you noticed what's common to these two ideas, and has nothing to do with porphyria? Changing shape; changing victims to be like themselves; difficult to kill.

These three have also been attributed to witches. The word "vampire" may even come from the Turkish for witch. So what we've got is just variations on an old theme with no real connection with the porphyrias.

Now for the third myth - madness! Why does everyone connect King George III with porphyria?

Some of his symptoms do seem to fit with an acute porphyria. However there are doubts. In those days no-one was allowed to touch royalty, even the doctors, so his symptoms are difficult to assess. Prof Peter's work suggests that he actually had gall-stones, and developed Alzheimer's at the end of a long life. DNA (genetic) testing, on some hair from his brush, failed to find anything indicating porphyria.

The idea that porphyria causes madness was also knocked on the head by a survey. This found that the incidence of mental health problems among porphyrics is the same as in the general population. The only difference was a slightly higher incidence of depression, something porphyrics share with all groups with long-term health conditions.

**If you come across any misrepresentation of the porphyrias, please let us know.** There was one in "Doc Martin" on TV recently. When we wrote to complain, the producer seemed to think we were lacking a sense of humour (they've never been at our meetings!). It confirms our feeling that the media are (usually) only interested in porphyria if it's sensational.

The National Portrait Gallery took Dr Stewart (from Hope Hospital, Salford) a little more seriously, and changed a label attributing King George's "madness" to porphyria. They deserve a pat on the back for a sensible reaction.

## Autumn Conference and AGM 2010

Our autumn conference, including our brief AGM, will be held next year in Cardiff, at the University Hospital of Wales. It will be on Saturday, 25th September, 2010, starting at 2pm.

It will start with the AGM, and then there will be talks by porphyria experts from the Hospital, a talk on EPP by one of our members, and a question and answer session.

There will be a chance to talk to other members to share your experiences with porphyria.

## International Meeting, Thursday 14th April 2011, in Cardiff

**Back in 2006 we attended an international meeting of support groups in Rome.**

**We have been keen to have another such meeting of support groups, and we are planning to have one next year, on 14th April, 2011.**

Every 2nd year there is an international conference on Porphyrins and Porphyria, where the experts meet. Last year in was in Stockholm. Next year it is to be in Cardiff, Wales. We agreed with the UK porphyria experts that if we had a patients conference immediately after this, then the medical experts would already be present, and would simply need to stay an extra day to talk at our conference. So we are arranging to have a patients meeting on the day after the Porphyrins and Porphyrias conference. It will be at the same venue as the main conference was on the previous 3 days.

We are starting to plan this patients conference. Our present thoughts are to have talks both by medical experts, and also short talks by people from the porphyria patient support groups. As with Rome, we are expecting that two groups of people will come to the conference. There will be representatives of the various international support groups, and also individual porphyria patients, especially those fairly local to the conference.

You are warmly invited to come to this conference.