

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER



Registered Charity No. 1089609



NEW FUNDRAISING INITIATIVE SPECIFICALLY FOR EPP PATIENTS

We are launching a new fundraising initiative and separate account for the benefit of those members who have EPP. We have found that a large number of the requests we receive for grants are from patients with EPP requiring financial assistance for protective films. As we are a small charity, with a very limited income, and no specific fundraising department or team, we felt that in order to continue to offer grants of this nature, a separate account designed specifically for this purpose would be ideal.

We already have the Helen Gibbs fund, which has successfully raised large funds, over the last few years, specifically for research into the acute porphyrias. This fund has a team of volunteer members who are continually organising events throughout the year. The

BPA is extremely grateful for their contribution as without their sustained fundraising we would be unable to continue to financially support research which we hope will help in the future of all those with acute porphyria.

The new fund will be called the EPP FUND. We will start the fund off with a deposit of £250 and hope that those of you with EPP will work together to keep this fund viable so that we can continue to provide screening for ALL members with EPP on limited income who need it. The costs to provide screening for a car are approx. £400. We have set a fundraising target of £3000 per annum which would enable us to provide screening for 8 cars. We can help YOU by providing fundraising advice, advertising materials, t-shirts, cotton bags and sponsor forms.

"WE CAN HELP YOU BY PROVIDING FUNDRAISING ADVICE, ADVERTISING MATERIALS, T-SHIRTS, COTTON BAGS AND SPONSOR FORMS"

We would suggest that you use the Facebook connections to help each other with ideas, or even to club together to organise bigger events. You may be able to get your friends, family and work colleagues to help you too. Here are some simple ideas, that are easy to organise with little time and effort

- Dress down days at work/school
- Coffee mornings
- Raffles
- Quiz nights
- Car cleaning
- Dog walking
- Beetle drive
- Games nights

Any funds raised should be sent to our treasurer with a covering letter of how they were raised and we will put the results of ALL events in our newsletter. We can also advertise any proposed events on our website and Facebook pages.

Please help US to help YOU!

MONTHLY HAEM ARGINATE

My name is Julie. I have AIP and some years ago I was a member of your organisation along with my mother Pauline Bradshaw who I believe is still an active member of your group.

I am a mother with a 5 year-old daughter and I also work full time as a Registered General Nurse. I have suffered many severe attacks (hospitalised for more than 4 weeks) during my life, starting in my early teens.

I would just like share my preventative treatment regime with yourselves as I feel it may offer another scope on the use of Haem Arginate to your members. My attacks are closely related to my menstrual cycle and therefore I now receive a single dose of Haem arginate 2-3 days prior to the onset of my monthly menstruation. I also have a Portacath implantation in my chest wall to provide central venous access as my

peripheral venous system is inaccessible after years during which the drug was given into peripheral veins.

I have tried many different patterns for regular infusions to prevent attacks (weekly, fortnightly, full four dailies and one off stat doses) as well as hormone suppression treatments, yet it has been the single monthly infusion with very careful timing to coincide with my monthly cycle that has proved by far the most effective.

Throughout my teens and 20s I often had severe attacks every month, in fact in reality one attack never truly passed before the next one began. Much trial and error occurred in my treatment during those years, but with the help of my local consultant Dr Norton and with a lot of advice from both Dr Mike Badminton at Cardiff and Professor Tim Cox at Addenbrookes, I finally found a routine that worked for me



"I HAVE BEEN HAVING THIS CAREFULLY TIMED MONTHLY INFUSION OF HAEM ARGINATE FOR 3 YEARS"

to prevent severe attacks and one that fits into my life as a busy working mum.

I am now in my 30s and although I continue to have occasional mild to moderate symptoms, my last severe attack was 2 years ago. I have been having this carefully timed monthly infusion of haem arginate for 3 years.... it took some time to settle my body down and into the routine but its been my life

saver, in more ways than one i.e. I now actually have a life :) Keep up the good work BPA.

BPA comment: *For the vast majority of patients haem arginate is only useful to treat severe acute episodes. It is not licensed to prevent attacks; and such use is undertaken only in exceptional circumstances at the advice of a porphyria expert.*

BABY NEWS



For those of you that know the BPA's Vice Chairman, you will be delighted to know that Liz and husband James had a baby boy, Thomas James, on 28 July 2011.

Liz has suffered from regular and severe attacks of acute intermittent porphyria for

15 years (often triggered by hormonal changes). Despite this, recent research has shown that pregnancy is remarkably well tolerated – even for those who have experienced severe attacks – therefore medical professionals were cautiously optimistic about the idea of her getting pregnant.

Liz's AIP stayed under control with regular weekly haem arginate infusions throughout the pregnancy and close monitoring from her porphyria specialists.

Baby Thomas was born by caesarean section at 37 weeks and is fit and well. He is being tested for AIP using a genetic test which takes swabs from the inside of his cheek to collect DNA.

FUNDRAISING NEWS

We would like to say a big thank you to everyone who has raised funds for the association in the past 6 months. Please continue to let us know how you are raising funds and send us your photographs.

In September trustee Karen Harris raised £462 by organising a 10km sponsored walk in Gravesend. Around 40 people took part to complete the circular walk. This is the second year that Karen has organised the event with the help of sponsorship by Bodywise Pilates, (www.bodywiseonline.co.uk) who kindly covered the costs of advertising and insurance for the event. Karen says that she was a little disappointed with the turnout for the event, which was down by 25 this year, as she had hoped for more people to participate.

£520.08 was donated via the Just Giving site which included £110 from Brian Chapman from his sponsorship raised doing the Darnley Trail Walk.

Jessica Byrne donated £104.37.

The Helen Gibbs Trust raised £1,176.22. The majority of this was raised by a group of friends doing the 10K Two Castles Run from Warwick Castle to Kenilworth Castle on Sunday 12 June 2011, in memory of Helen. Please see www.JustGiving.com/thehelengibbstrustfund if you need any more info on this.

Danielle Baker raised £149.50 which included £115 which was specified as being raised from the Birmingham Marathon on 11/9/11.

PROBLEMS WITH STUDYING

We have heard one or two disturbing stories from people who have been trying to study, or start a course of study. Both colleges and correspondence courses can cause problems.

Though colleges are expected to provide facilities for the disabled, people with a porphyria don't fall into a nice neat "wheelchair friendly" slot! Courses can sometimes include field-work in summer months, which is obviously not good for someone with EPP or another sun-sensitive porphyria. Even if you are mostly working from home, there are likely to be sessions at a centre, for tutorials or learning weeks, and the exams can be held there too.

For those who have intermittent, unpredictable illness, the problem can be deferring the course until you are fit enough to continue. Some colleges cope well with this, but others don't. Information on what to do in the case of illness is sometimes lacking, and ringing up often gives you someone who really doesn't know the system.

So before you start a course, preferably find out what you will be expected to do during the course. Will there be field-work, will you have to walk far (how many hours on your feet, if they can't tell you distances)?

Register your disability/health problems at the start. The college can't then complain that you haven't informed them. Write a short letter to your tutor, or the person in charge of the course. Send them a copy and give one to anyone who teaches you or lectures to you.

Get hold of the disability officer, or who-ever acts as one. Get a written statement of what can be done to help you, and what to do in the event of illness. If they can't provide one, ask for an email with details. Don't be put off – all organisations should have a disability policy.

Basically, the more you research and the more information you can get, the better your chances of getting through the course successfully.

Good Luck!



DON'T BE PUT OFF – ALL ORGANISATIONS SHOULD HAVE A DISABILITY POLICY

HOSPITAL OPEN DAY AT SALFORD

MANCHESTER, 23 JUNE 2012

Next year, on 23 June 2012, we are having an Open Day at Salford Royal Hospital (it used to be called Hope Hospital). It will include several talks on porphyrias by leading experts from the hospital, and by a patient, giving their experiences. It will also include a tour of the pathology laboratories for BPA members; where patient samples are tested, to confirm their porphyria, find the type of porphyria, or confirm that they are having an attack. **It will start at about 10.30 am, and finish mid-afternoon.**

BPA'S WEB-SITE UPDATE

Earlier this summer the BPA updated our web-site. It is at www.porphyria.org.uk The menu is a lot more detailed. So we hope that although there is more on the site, it still should be easier to find the information you want. You can click on either the main headings, or on one of the drop-down menus.

If you haven't already done so, do have a look at our new web-site. If you have any comments on our site, do let us know.

From the web-site you can get to the safe drugs list, which has been substantially updated in the last month.



RESEARCH GRANTS

We have been asked to consider helping to fund several new research projects, two of which we feel would be extremely beneficial to us all.

They are:

1. The development of a fast diagnostic genetic test for porphyria.
2. A study which explores autoimmunity in porphyria.

We are extremely excited about these projects which we would like to support, however, we would need to raise at least £7,500 to support one and possibly £15,000 to enable us to support both.

Our ability to do this is entirely in YOUR hands! What can you do to help us raise these funds? Do you need some ideas? Have a look at our fund-raising ideas on our website: www.porphyria.org.uk

We can help you with sponsor forms, press releases, advertising materials, t-shirts, cotton bags, etc. As a committee we all do as much as we can to raise funds ourselves. For example, Karen has run two

events so far this year raising over £700, with plans for a third event and hopes of topping £1000.

Let us know of any events that you plan. We can let other members living in your area know by advertising them on our website and Facebook pages.

If you see that a member living close to you is organising an event, why not offer your help or go along and support it.

Try to get your friends, colleagues, and family involved too, it can be great fun and it doesn't need to take up too much time.

Please help US to support research which will help US and the future generations.

