

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



MATTHEW BINNS - THE 3 BIG ONES - FUNDRAISING IN 2012

Around 5 years ago, during a drunken discussion with his brother-in-law, Matthew Binns agreed to attempt a triathlon, very challenging as he had not done anything remotely sporty for more than 20 years. However, Matthew was motivated by this one-off event and the sense of pride in reaching small but significant goals of the 400m swim, without stopping, the 30 minute run and biking in a peloton!

With much determination and hard work, Matthew completed his first triathlon and he became hooked on these challenging events! Matthew has since completed: ½ marathons, full cross-country and road marathons and other events, including open water swims. Matthew became addicted and over the next few years he became an active member of his local triathlon club, One Life Racing, where he has developed some great friends which have helped motivate him further. Matthew continued training and completing triathlons and at each

event he would stand at the edge of the water thinking why, and at the end thinking when is the next one!

Matthew accepted that he would never be a winner so he turned his attention to finding new and greater challenges. Which is why he developed: Binnsey's Big 3! Matthew is planning these 3 events as a personal challenge and he decided that with all this sweat, pain and exhaustion he should try to raise some funds for the BPA. Porphyria is close to his family's heart and Matthew hopes that his efforts this year to raise £1000 can go in some way to support the work of the BPA.

Matthew quotes: "It goes without saying that endurance events take a lot of time for training and a lot of effort to achieve, and I wouldn't have achieved any of these results without the loving support of my family and in particular my beautiful wife, Kristina, who constantly ensures that I stick to my training plan and is always on hand to patch up my aches and pains. I couldn't do it without you, Kris!"

IF YOU WOULD LIKE TO FOLLOW MATTHEW'S PROGRESS AND SUPPORT HIS FUNDRAISING ACTIVITIES, PLEASE SEE HIS JUSTGIVING PAGE:
WWW.JUSTGIVING.COM/BINNSEY-BIG-3.

Matthew Binns is completing the following '3 Big Ones' in 2012:

Marathon of the North

06 May 2012
Stadium of Light, Sunderland

Epic Swim

15 July 2012
Ullswater, Cumbria

Vitruvian ½ Ironman

08 September 2012
Rutland Water, Rutland

SCENESSE GOES TO EUROPEAN REGULATORS

Most of our members with EPP will be aware of recent trials of a drug called Scenesse or afamelanotide. The producers, Clinuvel Pharmaceuticals, are confident that they have shown its safety and its effectiveness in reducing sun-sensitivity. So they have submitted a Marketing Authorisation Application to the European Medicines Agency.

If it receives approval under EMA's Centralised Procedure, Clinuvel will be free to market Scenesse in all 27 EU countries,

plus Norway, Iceland and Liechtenstein, making it easily available for anyone with EPP.

It is likely to take the rest of the year to process the application. Clinuvel are also applying to NICE in the UK later in the year, to make Scenesse available on the NHS.

Since many people who took part in the trials found it very helpful, members who weren't involved may wish to try it if approved. However, as with any drug, be aware that there may be side-effects. These can vary a lot between individuals.

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Afamelanotide 16mg controlled-release formulation (SCENESSE®)

Afamelanotide, the active ingredient in SCENESSE-R, activates eumelanin, the dark pigment, in skin. Eumelanin protects skin from light and UV radiation (photoprotection). SCENESSE is administered underneath the skin as a dissolvable implant, approximately the size of a grain of rice, which activates eumelanin for a period of two months.

A NEW NATIONALLY COMMISSIONED SERVICE FOR SEVERE ACUTE PORPHYRIA

On April 1st 2012, a National Acute Porphyria Service (NAPS), commissioned and approved by the Department of Health, was started for patients living in England. It is led by porphyria specialists from the University Hospital of Wales in Cardiff, Kings College Hospital in London, and Addenbrooke's Hospital in Cambridge. The service will help patients who have frequent acute attacks,

and those who have had a recent one-off attack. Doctors at one of these three specialist centres will liaise with doctors at the patient's local hospital to provide a shared but coordinated service.

Patients will continue to receive most of their care at their local hospital, but they will occasionally attend clinics at one of the specialist centres. The specialist porphyria

centres at Leeds and Salford will hold regular outpatient clinics in conjunction with the National centres for patients living in the North of England.

Unfortunately many patients with acute porphyria, as well as those with other forms of porphyria, are not eligible for the new service. However, they will still be able to access expert care in the usual way through a GP referral to a

porphyria centre. If you are struggling with your porphyria, please contact us and we will help you to identify the specialist centre/doctor nearest to you and explain how you can seek a referral.

SPECIALIST CLINICS WILL ALSO BE HELD IN LEEDS AND SALFORD TO MAKE IT EASIER FOR PATIENTS LIVING IN THE NORTH OF ENGLAND.

FUNDRAISING

At the committee and trustee meeting held in March members discussed innovative ways to continue to raise funds. Several ideas were discussed, but one idea that we are considering is to run a "100 Club".

The basic feature of the BPA 100 club Lottery would be as follows:

- For a payment of £5 each month, by standing order, members of the 100 Club

will be allocated a Draw Number which will be entered into a monthly draw with a maximum of 100 fellow supporters of the BPA.

- Lottery income will be £6000 per year if 100 contributors take part
- Half the total proceeds will be allocated as prizes, totally £3000 per year
- There will be a monthly draw with the following prizes:

- 1st monthly prize £100
- 2nd monthly prize £75
- 3rd monthly prize £50
- 4th monthly prize £25

We feel this will be a popular way of raising money for the association because of the good chances of winning one of the 48 prizes to be drawn each year and sharing the £3000 prize money.

Anyone will be able to buy more than one Draw Number. A set of specific rules will be drawn up and the club would be licensed and operate under

local authority lottery rules.

In order for us to assess whether this would be a viable fundraising venture, we would be grateful for your feedback.

If you would be interested in taking part please complete and return the form below to: BPA Lottery, 14 Mollison Rise, Gravesend, Kent. DA12 4QJ, or email us at info@porphyria.org.uk (we can send your application form and club rules via email to save paper and postage).

Name.....Address.....

PostcodeEmail.....

I am interested in taking part in the BPA 100 Club lottery, please send me an application form and club rules.

TRAVELLING WITH AIP & HAEM ARGINATE – SUE BURRELL'S STORY

At the age of 28, in February 2008, I had my first AIP attack; I proceeded to spend periods of time in hospital over a two-year period while the doctors tried to get my AIP under control. A variety of treatments were tried to suppress my attacks, but haem arginate seemed to be the only treatment that worked. Haem arginate is a treatment that needs to be administered directly into a vein. Unfortunately, I have weak veins and the hospitals struggled to administer the medicine. After much deliberation, I was guided to have a portacath fitted under the skin in the upper area of my chest. This provides direct venous access for the treatment I need. Over a following two-year period, I began having treatments at home, delivered by qualified nurses through a home care provider. The nurses trained myself and, then a few months later, also my husband-to-be to access my portacath to deliver my treatments.

I am now able to lead what I feel is a 'normal' life and after getting married in October last year, we travelled to Las Vegas and then Mexico on our honeymoon where I took all my medication in a suitcase with me on the plane. This meant that we managed to have the honeymoon of our dreams! In February 2012 we travelled overseas again and went on a snowboarding holiday to Andorra - during this time I again needed to administer a treatment whilst away. My health restricts me from being as active as I once was, but I can now at least do some of the things I love to do, even if I do not have the energy to do them to the same level as I once did.

I feel that my portacath and determination to deliver my treatments independently has given me my independence back and I now feel that I have a greater control of both my AIP and my life. I do still regularly have attacks and suffer with leg, back, abdominal pain and sickness, but the self-administering of roughly three treatments each month helps to control my AIP wherever I plan to go in the world. I do need to plan things a little more than most people as I need specific documentation from my specialist whenever I travel with my medicine, and need to inform airlines about the things I need to carry, however I can now carry on my life in a fuller way. I have included a couple of pictures from my travels - I hope they will act as an inspiration for others who may be struggling at the moment!



I AM NOW ABLE TO LEAD WHAT I FEEL IS A 'NORMAL' LIFE AFTER GETTING MARRIED IN OCTOBER LAST YEAR

BRITISH PORPHYRIA ASSOCIATION GREAT DAY OUT

AT LEEDS CASTLE IN THE HEART OF THE KENT COUNTRYSIDE

SUNDAY AUGUST 19TH 2012

Join us on a fantastic day out at Leeds Castle in Kent and meet some of the BPA committee and other families living with Porphyria.

Known as 'The Loveliest Castle in the World', it is surrounded by a moat and set in beautiful landscaped grounds. For those who have restricted mobility Elsie the Castle Train runs from the entrance to the castle (50p each way).

There will be a tour of the castle in the morning, followed by lunch and a chance to socialise. Why not bring along a picnic or if you prefer lunch can be bought in the cafe. In the afternoon you may wish to explore the beautiful grounds and gardens. Children aged 5 to 15 can let off steam in the Knights' Realm Playground, a scale model of the castle built entirely of wood. The Toddlers' Play Area close by is designed for under 5s. Lose yourself in the yew maze, and return to civilisation through an underworld grotto. The Turf Maze is designed for younger children, the circles of turf lead to a small wooden castle. Entrance to all of these attractions are included with your admission ticket. You could also take to the water for a new way to see the Leeds Castle estate. The Black Swan Ferry Boat takes passengers across the Great Water from the castle drive to the maze and play areas (a charge of £1 each way applies, under 4s free).

We have a limited number of tickets for Sunday August 19th, which we will be partially funding in order to offer you a really great deal. So don't miss this great opportunity for a fantastic day out. Places will be allocated on a first come first served basis. If you would like information regarding accommodation in the area, please request it with your ticket application.

Adult tickets normal price £19.75
BPA price £12.50
Over 60s normal price £17.50
BPA price £11.50
Children aged 4 – 15
normal price £12.50
BPA price £9

To order your tickets please complete the form below and send a cheque made payable to The British Porphyria Association and post to: - BPA Great Day Out, 14 Mollison Rise, Gravesend, Kent. DA12 4QJ.

This year we are piloting this members' social event. If successful, we hope to organise other events across the country. If you are unable to make this event, but would be interested in attending others, please email us to let us know what sort of events you would be interested in. (info@porphyria.org.uk)

The BPA reserves the right to cancel the Great Day Out if enough tickets are not sold.

BPA Great Day Out, Leeds Castle, Sunday August 19th 2012

Name.....

Address.....

Postcode Phone number.....

Email Address

I would like to purchase the following number of tickets:

..... Adults @ £12.50 Total cost

..... Children @ £9 Total cost

..... Seniors @ £11.50 Total cost

TOTAL COST.....

I enclose a cheque made payable to The British Porphyria Association.

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

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: Sarah Pepperdine

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.

HOSPITAL OPEN DAY AT SALFORD

Manchester, 23rd June, 2012

On 23rd June 2012, we are having an Open Day at Salford Royal Hospital (it used to be called Hope Hospital). Registration is from 10am, for a 10.30 start.

In the morning we will have talks by patients, giving their experiences, and then the latest information on porphyrias by leading experts from the hospital.

After lunch (provided) we will split into two groups – one with patients with acute porphyrias (AIP, VP and HCP), and the other with those with skin porphyrias

(EPP, PCT, etc.). There will be a tour of the pathology laboratories where porphyria patient samples are tested, to confirm their porphyria, find the type of porphyria, or confirm that they are having an attack. Also the skin porphyria group will discuss advice on protecting the skin from light.

The meeting will finish mid-afternoon.

If you want to come, let us know.

We need to know names and numbers both for catering, and also for hospital security.

AUTUMN CONFERENCE 2012 IN CAMBRIDGE

Sydney Sussex College, 27 October, 2012. 2pm-6pm

This year we are holding our annual Autumn Conference at the William Mong building in the historic and picturesque setting of Sydney Sussex College, Cambridge.

The BPA's AGM will be held during the afternoon sessions. We are planning on coordinating an informative and enjoyable conference where there will be talks from different medical professionals on both the skin and acute porphyrias by experts from Addenbrookes Hospital Cambridge, as well as more informal talks/sessions from other patients

with both acute and skin porphyrias.

In addition, we are hoping to provide more information on how our new celebrity patron, Warwick Davis, is planning on supporting the BPA in their future endeavours.

We very much hope that many of you will be able to come to this friendly and informative meeting where patients, their families and medical professionals will be present. You can advise us that you will be attending, or, if you would like any further information, you can contact Sue Burrell via: helpline@porphyrria.org.uk.

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, 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:
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