

# THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER



Registered Charity No. 1089609



## NATIONAL ACUTE PORPHYRIA SERVICE (NAPS)

**T**he National Acute Porphyria Service (NAPS) started on April 1st 2012. It has been funded by the Department of Health to help patients with severe acute porphyria and is delivered by three National Acute Porphyria Centres: Cardiff (Dr Mike Badminton), Kings College Hospital, London (Dr David Rees), and Cambridge (Prof Timothy Cox, Dr Penny Stein). They work in partnership with two Regional Porphyria Centres in Salford (Prof Felicity Stewart) and Leeds (Dr Julian Barth), and specialist clinics are held at all five centres.

### Who is included?

NAPS focuses on the most severely affected patients with acute porphyria (acute intermittent porphyria, variegate porphyria or hereditary coproporphyrin). Patients are eligible either if they have been admitted to hospital with an attack in the last two years, or if they are on treatment to prevent attacks, such as regular haem arginate infusions or drugs suppressing ovulation. Patients must also be living in England.

### How does NAPS work?

When a patient is admitted to hospital with an attack, the hospital doctor should telephone NAPS. NAPS doctors will help doctors at the patient's local hospital to provide the best possible care. This may include sending haem arginate by courier, and giving advice about intravenous fluids, safe drugs, and pain control. When the patient leaves hospital, they will be offered an appointment at one of the National or Regional Centres as well as receiving care from a doctor at their local hospital who will be guided by a porphyria specialist.

All patients on regular haem arginate or other treatments to prevent attacks should be under the care of NAPS. They will continue to receive much of their treatment at their local hospital. However, they will also have the opportunity to see a porphyria specialist at one of the National Centres, as well as experts who can help with related problems, such as pain, kidney damage,

or coping with illness. Patients needing regular haem arginate can usually be offered the possibility of having this treatment at home with nursing support, if preferred.

### How will patients benefit?

Because porphyria is so rare, it is difficult for all doctors to get the experience needed to give patients the best possible care. NAPS means that patients having acute attacks can benefit from immediate specialist support wherever they are.

### What about patients who are not eligible for NAPS?

Many patients with acute porphyria, as well as those with other forms of porphyria, are not included in NAPS, but would still benefit from seeing a specialist. These patients should visit their GP to request a referral to a specialist centre. Patients living in Scotland, Ireland and Wales can also request GP referral to a porphyria specialist.

# RIDE LONDON 100 AUGUST 4TH 2013

Ride London 100 will be a new event organised by the London Marathon team. Next year will see the inaugural event. It will be the first charity Bike event of its kind. If you or someone you know is a regular bike rider and could complete 100 miles in less than 9 hours, please consider applying for a place. You can do this now at the following website:- <http://www.ridelondon.co.uk/Events/100.htm>

20,000 amateur cyclists are expected to take part in the inaugural RideLondon100. However, it is anticipated that the event will be over-subscribed and that a ballot will be held to allocate places in the event.

Successful applicants will be advised mid to late February 2013. If you are successful, please let us know and we will provide you with sponsorship forms and a t-shirt. We are really excited

to have been allocated 2 'golden bond' places in this event. If you enter the ballot and are unsuccessful you will then be able to apply to us for one of these precious places. These places will be conditional on your pledge to raise a minimum of £500 for the BPA. Application forms for our 'golden bonds' will be available on our website in the new year.

[www.porphyrria.org.uk](http://www.porphyrria.org.uk)



20,000 AMATEUR CYCLISTS ARE EXPECTED TO TAKE PART IN THE INAUGURAL RIDELONDON100.

## BPA OPEN MEETINGS, 2013

Next year the BPA are organising two public events for our members. We are having a porphyria **Open Day** at Kings College Hospital, London, on Saturday 8th June 2013. Our Open Days are always popular; and as usual this event will include talks on porphyria by clinicians from Kings, and also a tour of the porphyria testing laboratory. Our **Autumn Conference** next year will be in Scotland for the first time. It will be in Dundee, on Saturday 21st September 2013. This will include our brief AGM, but with much more time given to talks by Scottish clinicians, and porphyria patients.

## INTERNATIONAL PATIENT MEETING

Also next year there is an International Patient Conference in Lucerne, Switzerland. Quite a number of you came to the previous international patient day last year in Cardiff. We had very positive feedback about it. If you fancy a holiday in Switzerland, why not come to this one-day conference, on 18th May 2013. It will include talks by doctors on the latest information on porphyria, and talks by patients and patient organisations.

## A HUGE THANK YOU TO THE CHAPMAN FAMILY FOR THEIR FUNDRAISING ACTIVITIES IN 2011 AND 2012

Sarah Kate Chapman is a 7 year old girl with EPP and in the last few months, Sarah's brother Matthew has also been diagnosed with EPP. Both children have to be very careful to protect themselves from sunlight, otherwise they suffers with horrible burning sensations and swelling of their skin. Both children have amazing characters, and instead of hiding away from the world, they have been working hard, with their family in Sunderland, to not only raise awareness about EPP and porphyria in their area, but also to raise funds for the BPA.

The BPA would like to thank Bryan Chapman, their dad, for the Coast to Coast Cycle that he did which raised over £500.00. Gillian, their mum, has also fuelled a number of events to help raise funds for the BPA, including a sponsored Penalty Shootout at the local school which raised over £500.00 from sponsorship and raffle prizes which were donated from local business. In addition, Sarah and her sister Rebecca attend the Valerie Shepherd Dance Academy and their production of the Christmas show managed to

raise nearly £800.00 for the BPA. The Chapman family, Gillian, Bryan, Rebecca, Sarah and Matthew have all been very busy and have raised an amazing £2,000 for the BPA - we are extremely grateful for all their hard work for raising funds and for raising awareness of EPP and porphyria in general. We would like to give thanks to the Shields Gazette for the picture below which shows

just how much fun can be had from helping to organise and partake in charity events.

Once again, a huge THANK YOU to the Chapman family for all their amazing efforts in raising awareness and funds for the BPA (I know they have ideas for more events planned for 2013, including: people running in the Great North Run for the BPA and a 60 mile sponsored walk) - please keep up the great work!

SARAH AND HER SISTER REBECCA ATTEND THE VALERIE SHEPHERD DANCE ACADEMY AND THEIR PRODUCTION OF THE CHRISTMAS SHOW MANAGED TO RAISE NEARLY £800.00 FOR THE BPA



# IRONMAN FUNDRAISING

This summer, a husband and wife team – Rachel and Kevin Wright – raised £900 for the BPA by completing the IronMan triathlon in Switzerland.

Cyclists, if really keen, complete long distance races of about 120 miles. Similarly, very keen runners complete marathons. Really mad people, like Kevin and Rachel, combine both of these two events immediately after swimming for two and a half miles! These three sports are done consecutively – to form the IronMan triathlon. Top athletes complete this combined event in around ten

hours, but for most people, like Rachel and Kevin, it takes between 14 and 15 hours.

This husband and wife team were supported by Rachel's parents, John and Kirstine Chamberlayne, whom many of you will have met before at BPA meetings. John and Kirstine took Rachel and Kevin to assess the course a few days before the race, they also supported Rachel in hospital when she strained her shoulder four days before the race (as she had fallen from her bike while training), and they finally took the exhausted couple back to their hotel after the race.



TOP ATHLETES COMPLETE THIS COMBINED EVENT IN AROUND TEN HOURS, BUT FOR MOST PEOPLE, LIKE RACHEL AND KEVIN, IT TAKES BETWEEN 14 AND 15 HOURS.

## WE NEED YOU!!

We are hoping that the articles in this newsletter might inspire you to support the BPA's mission to help raise funds to support the BPA's work, while also raising awareness in your area. If you have been inspired by the fundraising efforts in this newsletter and would like to begin raising awareness and funds in your area then the BPA can help you with ideas and offer support for your endeavours – including the bike ride that



we are looking for volunteers with. We can provide you with a Fundraising Pack, which includes a t-shirt to raise awareness and for you to wear at your event and sponsorship forms and information on how to set up a 'JustGiving' website page, for all people who aim to raise a minimum of £50.00.

Please contact the BPA if you would like further information, or if you have an event planned and would like a Fundraising Pack please get in touch.

## THANK YOU SHANEEN BROWN AND CONGRATULATIONS ON COMPLETING THE NEEDLES HALF MARATHON

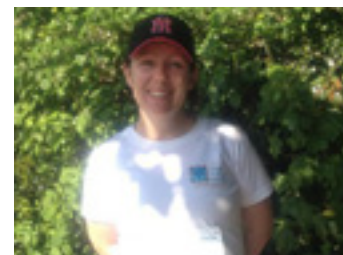
The BPA would like to give a massive congratulation to Shaneen who, in May this year, completed the Needles Half Marathon on the Isle of Wight, while also raising over £500.00 for the BPA.

Shaneen's sister had EPP and two holes in her heart and sadly in 1989, at the age of seven, lost her fight. Shaneen and her family have fond memories and Shaneen decided to run the half marathon to raise funds for the BPA in loving memory of her little sister who has been Shaneen's inspiration, along with her family's support, throughout.

Shaneen plans to run further events in her sister's memory to continue to raise fund for the BPA. The BPA are very

grateful for the funds and awareness raised by Shaneen and we are touched by the courage that we see her fight to raise funds and awareness of porphyria on behalf of the BPA and her sister!

If you would like to follow Shaneen's plight to raise awareness or if you would like to donate to Shaneen's efforts, you can do this via her Just Giving page: <http://www.justgiving.com/shaneen-brown>.



## WELL DONE MATTHEW BINNS ON YOUR BIG 3 ONES

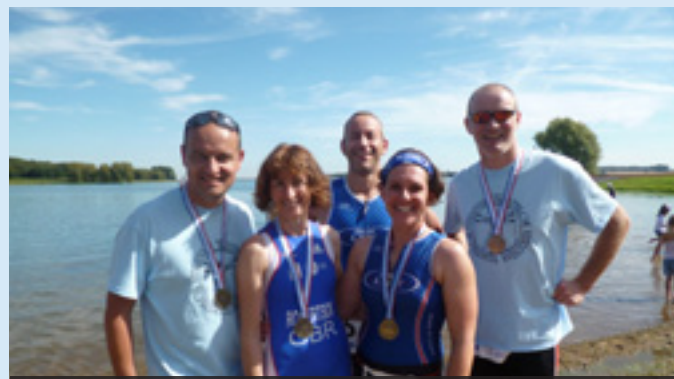
The BPA would like to say a massive THANK YOU and WELL DONE to Matthew who, in 2012, raised more than £1,600 for the BPA. Matthew has put his heart and soul, both physically and mentally, into the three events that he completed!

Over a period of months, Matthew completed three physically taxing events, including: a marathon in May, the Epic Swim in Ullswater in July and then finally a half ironman triathlon in September 2012!

The BPA would like to thank Matthew for all of his efforts, not only physically, but also in fundraising and raising awareness of his events, porphyria and the BPA – THANK YOU MATTHEW!

If you would like to learn more about Matthew's events, you can visit his Just Giving page to read more of his story or to donate to his efforts:

<http://www.justgiving.com/binnsey-big-3>.



WELL DONE TO MATTHEW WHO, IN 2012, RAISED MORE THAN £1,600 FOR THE BPA

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

web: [www.porphyrria.org.uk](http://www.porphyrria.org.uk)  
email: [helpline@porphyrria.org.uk](mailto: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  
Prof. Felicity Stewart

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# PROFESSOR STEWART IS OUR NEW PATRON

We are pleased to officially welcome Prof Felicity Stewart as an additional Patron for the BPA.

A number of us know her from attending her porphyria clinic in Salford, Manchester. She is a member of the BPA, and organised our first ever Porphyria Open Day in 2005, and then another earlier this year.

Prof Stewart was appointed as Consultant in Clinical Biochemistry in Salford Royal (formerly Hope Hospital) in 1994. As well as her clinical roles, she had a longstanding interest in medical education and was appointed as Hospital Dean (Salford Sector) and Honorary Professor in the University of Manchester Medical School in 2011.

She has been responsible for the Specialised Porphyrin Biochemistry section of the laboratory in Salford Royal since 2000. They provide a regional service for the diagnosis of all forms of porphyria. The service was recognised

internationally as a specialist centre by the European Porphyria Network in 2006.

In February 2008, she took over Consultant responsibility for the tertiary referral clinic for patients with all forms of porphyria, having worked in the clinic with Dr Russell Ead (Consultant Dermatologist) from 2001-2007.

Prof Stewart currently chairs the British and Irish Porphyria Network – BIPNET (formerly the Porphyrin Interest Group). Through BIPNET, we try to foster effective collaboration between specialist clinicians and scientists as well as strong links with patients through the British Porphyria Association (BPA). This year has been a very exciting one for BIPNET with the launch of the new National Acute Porphyria Service on April 1st 2012, development of a BIPNET website and forthcoming publication of BIPNET guidelines for the management of acute porphyria attacks.



## 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](http://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  
136 Devonshire Rd, Durham City, DH1 2BL

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