

# THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



## PLEASE JOIN THE BPA'S CHRISTMAS BAUBLE FUNDRAISER

This year, the BPA are selling beautiful glass Christmas baubles filled with snow. These baubles will make the most wonderful Christmas gifts for friends and family, secret Santa presents, teacher thank you gifts or even table decorations!

Each bauble has a beautiful wooden BPA heart on it and comes with a gift box and Christmassy red tissue paper. Pretty candy-striped twine ties another wooden BPA heart to the box to complete the precious package.

100% of all profits will go to the BPA, so you can enjoy these beautiful baubles whilst also supporting the BPA.

### Choose from:

- Christmas Tree Bauble £6
- Christmas Robin Bauble £6

### Price: £6 per bauble (plus £3 P&P per order of up to 6 baubles)

For orders of 5 or more baubles, the individual gift boxes will come flat packed with the tissue paper for you to pack separately (to save on postage).



### When ordering, please make sure you indicate:

1. Whether you would like a Christmas Tree or Robin design (and how many of each).
2. Your name, postal and email address in the information section so that we can send you your order.
3. You can also leave a contact telephone number if you would like, in case we need to contact you about your order.

**If you place an order and haven't had an email from the BPA to confirm the order within 72 hours, please contact us on the details below.**

**You can get in touch with the BPA via:** [merch@porphyria.org.uk](mailto:merch@porphyria.org.uk) or you can leave a message on the BPA helpline telephone number 0300 30 200 30.

**Last date for orders guaranteed for Christmas delivery is Friday 4 December 2020.**

We hope you like the BPA's Christmas fundraiser idea! We'd also like to take this opportunity (we know it is a little early) to wish you and your loved ones a very Merry Christmas, from all at the BPA.

**Place your order now via Virgin Money Giving:  
[www.virginmoneygiving.com/fund/bpachristmasbaubles2020](http://www.virginmoneygiving.com/fund/bpachristmasbaubles2020)**



One of our long-standing patrons and a familiar face to many of you, Dr Mike Badminton, recently became a Professor. A professorship is the culmination of many years' experience and expertise within an academic field and it takes many years of well-renowned research to achieve.

**Congratulations, Professor Mike Badminton!**



We would like to wish a fond farewell to Tricia Gardiner who retired in August 2020. For many years, Tricia was the specialist porphyria nurse based within the National Acute Porphyria Service (NAPS) team in Cardiff. Tricia's caring and compassionate support of patients will be most definitely missed by many patients and by us at the BPA too.

**Wishing you a happy and fulfilling retirement, Tricia!**

## SAVE THE DATE: PORPHYRIA AWARENESS WEEK:

**10-17 APRIL 2021**

The BPA are currently planning our 2021 Porphyria Awareness Week campaign and hope that it will be as successful as 2020! For the minute though, please make a note of the date: 10-17 April 2021.

In 2021, we plan to have a week of awareness and fundraising that we hope many of you will engage with again. If you would like to share your story, get involved in a fundraising or awareness activity then please get in touch and we can help you plan/coordinate things.

We'll be updating our website, social media and email communications with our exciting plans as they develop. You can also get involved by getting in touch on [helpline@porphyria.org.uk](mailto:helpline@porphyria.org.uk) or 0300 30 200 30.

## VITAMIN D AND COVID-19

Vitamin D helps regulate the amount of calcium and phosphate in the body. It is important in providing nutrients to keep bones, teeth and muscles healthy. A lack of vitamin D can lead to problems with your bones, such as osteoporosis.

It also has an impact on immunity, and although the extent is not fully understood as yet, a growing body of research has suggested that Vitamin D may be helpful in the fight against Covid-19. It has been proposed as one of the possible reasons why black and ethnic minority patients appear to be more severely affected by coronavirus than the general population.

At the time of writing, the UK Government is developing guidance to advise everyone to take an over the counter Vitamin D3 supplement, especially during the winter months. The recommended dose is 10 microgrammes (400 IU) per day.

The advice for patients who may have increased susceptibility to Vitamin D deficiency (such as EPP patients) is even stronger. UK porphyria specialists advise that all patients who photoprotect should be taking daily Vitamin D3 at a dose of 25 microgrammes (1000IU), unless their blood results show that their Vitamin D levels are fine.

# CONNECT 2020: ONLINE... LIVE... TOGETHER...

We were delighted to welcome so many of you to our first ever online event on 19 September 2020. The webinar format integrated our AGM, a skin porphyrias interactive session, a kids EPP session, an interactive acute session and a social element with a quiz and discussion topics. A huge THANK YOU to all who took part in the day, enthusiastically answered the polls and asked so many brilliant questions. Your input was vital and culminated in some fascinating and enlightening discussion topics.

We're immensely grateful for the support of Dr Bob Sarkany (photodermatology), Dr Penny Stein (acute porphyrias), Dr Deepak Ravindran (pain), Dr Rukshana Ali (psychology), Dr Vicky McGuire (photobiology), Dr Stephen Lombardelli (Alnylam) and Dr Kirstine Belongie (Mitsubishi) who dedicated time to prepare and pre-record videos for the day, and then also took time out of their weekends to offer us all their support and advice in the interactive sessions. THANK YOU!

Finally, we'd like to offer a huge thank you to our sponsors, Alnylam Pharmaceuticals, Clinuvel and Recordati Rare Diseases. Your continued assistance enables us to continue helping and supporting porphyria patients and their families at important events such as this one.

## Feedback

Respondents rated the event as follows:

91/100

for how well it met  
their expectations

91/100

for the general  
content

79/100

for the Get Social  
element

## Your highlights

All of the pre-recorded content from the day is now available on our YouTube Channel as bite-sized videos on a selection of topics. You can view the videos here: <https://www.youtube.com/channel/UCP4eYSS1l01Xc1LxZ3l9eGw/videos> or search for 'BPA Connect'.

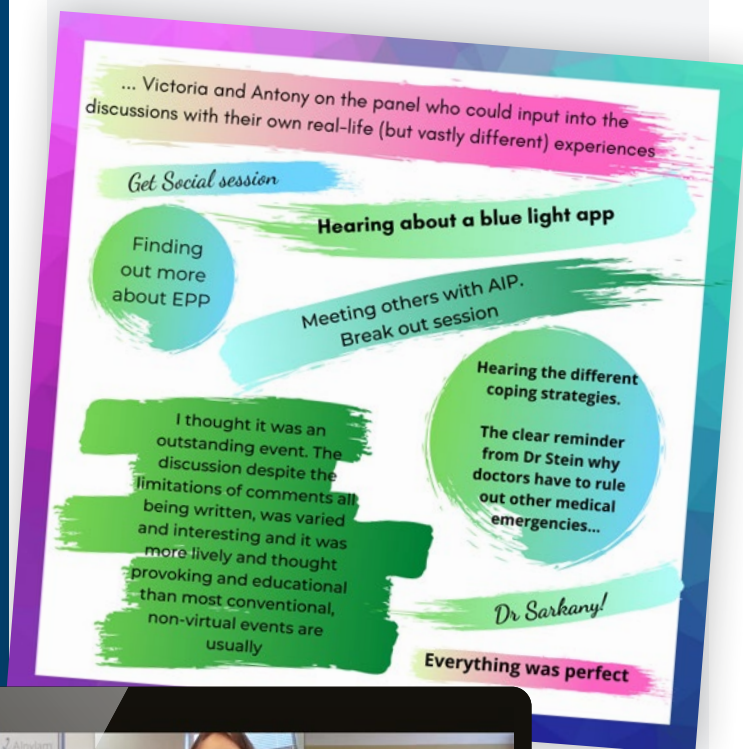
Questions asked during the day, as well as those that we ran out of time to ask our experts, have been formulated into a Q&A document and have been reviewed by our specialists. This document is now available on our website: [www.porphyrria.org.uk](http://www.porphyrria.org.uk)

The polls from the day gave us a great insight into what you as patients need from us and where we can develop events going forwards. Take a look at the poll results on [www.porphyrria.org.uk](http://www.porphyrria.org.uk).



We don't know what the next year will bring in terms of restrictions, but we are currently hoping to hold a face-to-face meeting in the centre of the country, which will likely be within easy reach of Birmingham or Derby. We are also planning to introduce a virtual element. As yet, we haven't decided whether that will be as part of the main meeting or as a separate event, and we are keeping plans fluid for the moment until we know more about the restrictions that we may be facing. But whatever happens, we'll be there to support you in 2021.

**We look forward to seeing you all again next year.**



# ROUTINE TESTS

We are often asked questions about what routine tests patients should be having. This depends on what porphyria you have, how severely you are affected, as well as what other complications you may have. Patients under the care of a porphyria centre will most likely have many of these tests done as part of an annual review. However, some patients will see local dermatologists or may have lost contact with a porphyria centre due to being quite well. If this is applicable to you, there may be times when it would be advisable to re-contact a doctor to ensure tests are completed.

There are no formal guidelines, but here's a quick guide to the types of tests you might expect your dermatologist or other doctor to be providing.



ACUTE PORPHYRIAS	
What test?	A urine test to measure urinary PBG (porphobilinogen)
Why?	Baseline levels of PBG when not in an acute attack can assist in diagnosis of an acute attack at a later point. The tests will require porphyria specialist interpretation, but can be helpful in some cases.
How often?	When a porphyria specialist thinks it may be useful.
What test?	A blood test to measure kidney function
Why?	Some people with acute porphyria can experience chronic kidney disease. It is thought that certain genes can make people with acute porphyria more susceptible to kidney damage.
How often?	Annually if experiencing regular attacks.
What test?	A blood test to measure liver function, or a liver ultrasound scan or MRI
Why?	Research from Sweden showed that acute intermittent porphyria patients over the age of 50 were at an increased risk of hepatocellular carcinoma (liver cancer). This has not been shown to be the case in the UK. However, as a precaution, patients with AIP are invited to a liver scan after the age of 50.
How often?	Over 50 years of age, this will be done annually.
What test?	Blood tests to measure ferritin levels (some patients will also require vitamin D, vitamin B12 and folate tests)
Why?	Regular haem arginate can cause iron/serum ferritin overload and some patients who suffer regular attacks may have lower than average levels of vitamins.
How often?	Patients having regular haem will be under the care of a porphyria specialist who will arrange for the tests to be done when needed.
What test?	Bone density scan
Why?	Patients who have been treated with Gonadotropin-releasing hormone (GnRH) therapy to suppress the menstrual cycle can be more susceptible to osteoporosis.
How often?	It might be done following treatment with GnRH or if blood tests reveal vitamin D or calcium levels to be low.

## EPP/XLEPP

What test?	A blood test to monitor liver function
Why?	A few people (less than 5%) develop liver complications as a result of their EPP, so it is important to monitor liver function.
How often?	Annually
What test?	A blood test to monitor iron levels
Why?	EPP patients can be anaemic, although results may require specialist interpretation as they commonly have lower levels of iron without it being problematic. Unless levels are very low, iron therapy is only considered with caution in EPP because the effect is unpredictable. Some people experience more phototoxic reactions after taking iron, and also problems in the liver, so they need to be monitored.
How often?	Annually
What test?	A blood test to measure Vitamin D
Why?	Due to the lack of sunlight, and the potential for reduced opportunities to exercise with weight-bearing activities, EPP patients can suffer from a vitamin D deficiency.
How often?	Annually
What test?	Bone density (DEXA) scan
Why?	Osteoporosis can be more common in people with EPP than the general population, due to lower levels of vitamin D and lower than average levels of weight-bearing physical exercise.
How often?	It might be done if blood tests reveal vitamin D or calcium levels to be low.

## PCT

What test?	A blood test to monitor iron / serum ferritin levels
Why?	Symptomatic PCT patients experience high levels of iron in the blood and these can lead to excess iron stores in the liver. If levels are high, venesection or phlebotomy (drawing blood) can help to reduce them. A unit of blood can be removed approximately every two weeks. The aim is to gradually reduce iron until the serum ferritin reaches a normal level.
How often?	When required
What test?	A blood test to monitor liver function or a liver ultrasound
Why?	A few people develop liver complications as a result of their PCT, so it is important to monitor liver function if the disorder is active. If liver function blood test results show impaired function, further liver testing such as a scan or biopsy might be done.
How often?	When required



**Despite the strange times we are living in, we are delighted to report that it hasn't stopped some dedicated fundraisers going the extra mile to support the BPA. We would like to say a massive thank you to everyone who has donated or been fundraising for the BPA over the last few months.**

- A massive WELL DONE and THANK YOU to our two virtual London Marathon runners (Paul and Melanie), who, on 4 October, braved biblical storms to complete their 26.2 miles!
  - Paul Gutteridge completed the event in just under 4 hours – a fantastic achievement. His girlfriend Frankie joined him for 10km which helped keep his spirits up, raising a wonderful £982.75 for the BPA.
  - Melanie Edwards really went the extra mile as the app didn't track properly. She was still smiling at the end and was supported on the day by her son Jamie, and partner Liam, who joined her for 10km, as well as other friends and family who joined her at various parts to offer encouragement to complete this lifetime achievement, all whilst raising a phenomenal £592.25 for the BPA.
- Across the summer the BPA held our Active21 campaign to raise funds. The BPA's own Sue Burrell, husband Ian and daughter Abi (aged 3) walked or cycled a collective distance of over 321 miles to raise £617.50 for the BPA.
- Faiza McKahey and the Scottish Cutaneous Porphyria Service in Dundee raised £401.00 for our Active 21 Campaign by each climbing 21 flights of stairs every day in September.
- Over the past few months, Natassja Chadwick has continued her fundraising mission, holding a summer disco, a dress-down day at Victoria Road School, a car boot fundraiser and a specific stall selling Christmas baubles and BPA merchandise on the Isle of Man raising an amazing £643 for the BPA. WELL DONE Natassja and THANK YOU to all your family and friends who continue to support your amazing awareness and fundraising efforts.
- Richard Bennett raised a wonderful £75 through a quick whip around and Richard Byford raised £110 during Porphyria Awareness Week.
- Alicia Cawthorne shared her story with Take a Break and donated her £200 fee to the BPA.
- Finally, THANK YOU to all who have nominated the BPA on Facebook for birthday donations. You have raised a wonderful £77.50 through the Paypal Giving Fund since June 2020.

**If we haven't named you individually here, it isn't because we don't care, we simply have limited space. Please be assured that all of your efforts and contributions, no matter how small or large, are massively valued and enable us to continue doing the work that we do. THANK YOU TO YOU ALL.**



Paul Gutteridge



Melanie Edwards, her son Jamie, and partner Liam



Sue, Ian, and Abi Burrell

# HELPLINE

## 0300 30 200 30

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.porphyria.org.uk](http://www.porphyria.org.uk)

email: [helpline@porphyria.org.uk](mailto:helpline@porphyria.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: Natassja Chadwick / Anne Newton

Secretary: Richard Bennett

Administrators: Sue Burrell and Liz Gill

Patrons: Prof George Elder, Dr Mike Badminton,  
Prof Felicity Stewart, Dr Penny Stein,  
Prof David Rees, Dr Bob Sarkany

Viewpoints 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.



## A Challenging 2020

Covid-19 has had a huge impact on 2020 which has been a strange and difficult year for many of us who have faced loss, as well as more challenges, hardship and uncertainty than normal! We wanted to remind you all that the BPA are still here for you throughout these difficult times and you can always get in touch if you need support via [helpline@porphyria.org.uk](mailto:helpline@porphyria.org.uk) or on 0300 30 200 30.

## THE BRITISH PORPHYRIA ASSOCIATION Registered Charity No. 1089609

### MEMBERSHIP / DONATION FORM



#### MEMBER DETAILS

Please complete (\*required field) and return to:  
**BPA Treasurer, Rothlea House, 7-8 Quarry Lane, Butterknowle, Bishop Auckland, DL13 5LL or email it to [treasurer@porphyria.org.uk](mailto:treasurer@porphyria.org.uk)**

Title \* Full name \*

Address \*

Postcode \*

Landline Mobile

Email

Type of porphyria

#### Are you a (please tick):

☐ Patient ☐ Relative ☐ Medical professional ☐ Supporter/donor ☐ Other

#### What information are you happy to receive? Tick all boxes that apply:

☐ All BPA communications ☐ Newsletters  
☐ Patient events/information ☐ Fundraising/awareness events

#### How would you like us to keep in touch with you? Tick all boxes that apply:

☐ Post ☐ Email ☐ Telephone ☐ Text message

#### DONATIONS

By making a donation to the British Porphyria Association you will know that you are making a vital contribution to our work. A suggested donation of £15 per year will help us raise awareness, man our helplines or support research.

#### I would like to make a donation of:

☐ £10 ☐ £15 ☐ £20 ☐ £25 ☐ £50 ☐ other £.....

#### WAYS TO DONATE:

- ☐ Cheque: made payable to the British Porphyria Association.  
☐ Online banking (one-off payment or regular standing order):  
BPA bank account: Sort code: 20-43-63, Account no. 7099 6904  
Please use your name and postcode as the payment reference.  
☐ Credit card: via Just Giving ([www.justgiving.com/britishporphyriaassoc](http://www.justgiving.com/britishporphyriaassoc)).  
☐ If you would prefer to complete a standing order form, please call us on 0300 30 200 30 and we will arrange to send one to you.

☐ I would like a receipt

#### 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.

#### GIFT AID DECLARATION

I am a UK taxpayer 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. 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