

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



GENERATION GENOME

Last year, BPA representatives and members of the porphyria community were involved in an exciting awareness and education project with Kent TV. KMTV are currently producing a factual television series on genetics called 'Generation Genome' along with the British Film Institute and the University of Kent. It is a six-part science series developed for an audience of 11 to 14 year olds. Each episode has two parts. The first half presents a genetic theme and highlight a series of case studies in a short documentary. The second half takes the form of a debate with a young audience and a panel of experts.

Sue Burrell (AIP patient) and Ava Pottle (EPP patient) were interviewed about their experiences with porphyria and how it affects their life. Later Ava and Sue discussed future treatments and what is currently available for treatment on the NHS. In the second half, Liz Gill and Ava were panellists in the audience debate.

The series has now been released and is available on YouTube. The episode that discusses the porphyrias is Genomic Medicine 4/6 www.youtube.com/watch?v=1KUybdKwtN8. Later, this resource will be distributed as a KS3 resource in schools across the UK, with a view to international distribution in the near future.



EVENTS 2022

The BPA have had a busy year hosting and attending some wonderful events and meetings. We would like to say THANK YOU to Alnylam Pharmaceuticals, Disc Medicine, Mitsubishi Tanabe Pharma and Recordati Rare Diseases – their sponsorship has helped to support our events, our Wellbeing Project and attendance of key BPA personnel at the International Meeting in Bulgaria. This support has enabled us to meet our strategic aims.

BPA Re-Connect in Dundee

In May, we were delighted to be back to a face-to-face event with over 40 people attending in person. As a first for us, we also LIVE streamed some sessions, which will be uploaded in due course to our You Tube Channel.

The Re-Connect event included acute and skin Q&A panel discussions, as well as sessions on the importance of physical and mental health. We were gratefully joined by some wonderful speakers, including Dr Vicky McGuire (who helped significantly in the organising) and Dr Robert Dawe from Dundee, Dr Bob Sarkany (London), Dr Danja Schulenburg-Brand (Cardiff/NAPS), Dr Peter Galloway (Glasgow), Dr Stephen Lombardelli (Alnylam Pharmaceuticals), George Mensing (Disc Medicine), Arlene Maitland (mindfulness) and Victoria Harrold (EPP patient story). The whole day was well received with 100% positive feedback for all of the sessions. But the BPA's highlight, after such a long time of delivering everything virtually, was bringing the porphyria community physically back together!

NEW PATRON

The BPA are delighted to announce Dr Vicky McGuire as one of our patrons. Dr McGuire is the Principal Clinical Scientist working at the Scottish Cutaneous Porphyria Service in Dundee. She is an active member of the scientific porphyria community, heavily involved in testing and research, and also the joint-chair of the British and Irish Porphyria Network (BIPNET).

Vicky became actively involved in the BPA in 2019 at our Festival Event in

Manchester where she brought a really fresh slant to the science behind porphyria. Since then, Vicky has been a co-contributor/organiser of our Re-Connect event in Dundee and was an active member of our volunteer team for the Connect Alfresco event in Leeds in October. We are very grateful for the support and time Vicky has already dedicated to the BPA and we look forward to future collaborations and support in the years to come.

EVENTS 2022

BPA CONNECT ALFRESCO IN LEEDS



Earlier this year, we were awarded £9,500 from the National Lottery Community Fund to support our first outdoor event aimed at young people and the EPP community: Connect Alfresco! HUGE THANKS to National Lottery players and the Community Fund for making this event possible. In October, we brought together 55 individuals, including 13 families with at least one member affected by EPP, at Temple Newsam, Leeds.

The day started with our AGM and a Lego workshop followed by a tree-top adventure at Go Ape. Children and adults helped each other to complete the various challenges! It was amazing to see friendships developing as the day progressed. The afternoon's team activities included a treasure hunt and an orienteering activity. The day was a huge success with attendees suggesting that it should be longer - confirming our hopes that a two-day or residential event in 2023 is worth exploring!



In addition to thanking the National Lottery Community Fund, the BPA would also like to thank Disc Medicine who helped to sponsor this event – their funds enabled us to bring two families from Ireland to attend the Alfresco Event. We were also grateful for all of our volunteers who helped throughout the event, including Dr Vicky McGuire and our Duke of Edinburgh volunteer, Parker Tapp.

INTERNATIONAL CONGRESS ON PORPHYRINS AND PORPHYRIA (ICPP)

The BPA had a busy week in September attending ICPP in Sofia, Bulgaria. After being delayed a year due to Covid, it was wonderful for the whole porphyria community of patients, patient advocates, scientists, treating physicians, researchers and pharmaceutical partners to come together to focus on porphyria!

Epnet update: Liz Gill (the Patient Representative on the European Porphyria Network – Epnet) attended various meetings and Working Groups, alongside Antony Fearn, in advance of the main Congress, to collaborate on international projects and research.

GPAC update: The Global Porphyria Advocacy Coalition (led by Sue Burrell) held their AGM with attendance from over 15 international porphyria advocacy groups. Alnylam Pharmaceuticals, Disc Medicine and Moderna also presented on the status of their research/medications. These early meetings fostered some wonderful discussions which continued into the main Congress.

Patient Day: This was the first ICPP Patient Day to be streamed LIVE, making it accessible to patients from across the world! Patient advocacy leaders joined patients from across the globe, including Bulgaria and neighbouring countries.

The day, designed for patients by patients, was planned by Louise McGovern and Dr Aneta Ivanova from Bulgaria – with support from key members of the international patient community. The day included global updates, as well as testimonials from local patients. Dr Jasmin Barman and Dr Amy Dickey also presented outcomes of patient-reported studies relating to EPP and acute porphyria. The day ended with a wonderful Q&A session. The whole day was engaging and thought provoking – we look forward to meeting again in Pamplona, Spain in 2024.

ICPP Main Congress: The main congress entailed scientific talks and presentations across three days. Of note, there were insightful discussions on the real-world experience of using Givlaari, as well as updates on new and emerging therapies. The POWER Study (Porphyria Worldwide Patient Experience Research) <https://onlinelibrary.wiley.com/doi/full/10.1002/jmd2.12343> detailed that internationally acute patients with sporadic or recurrent attacks were still experiencing significant disease burden and decreased quality of life. The cutaneous porphyria



presentations explored the new and emerging therapies of Dersimelagon and Bitopertin, which are in the early stages of clinical trials internationally. A noteworthy research abstract was presented by Dr Amy Dickey on light monitoring using a wearable/watch light meter (blue light dosimetry). Data gained using this method might be able to complement trial data to demonstrate factors which tend to be very difficult to track against EPP symptoms, such as time spent outside and weather variables (eg, full sun, rain, cloud).

Thought provoking discussions included topics such as clinical care guidelines, consistency and equitability of testing, care and access to treatments for all patients, irrespective of the countries they live in.

– WRITTEN BY KAY ABOUT HER INSPIRING GREAT NORTH RUN CHALLENGE

Some months back I decided to set myself a personal challenge and signed up for the Great North Run. I decided to fundraise for the BPA as they have been a great sense of support to myself and my family for many years now. I set up a JustGiving page with frequent posts regarding my training and my progress, I'm pleased and I'm shocked to say I've raised £970 for the BPA.

In April, I started my training. Initially I was running 5K twice a week, but I gradually built this up and my distance increased along with my stamina. I was soon enjoying and looking forward to going out for my training runs.

The week before the run I had to take advice again from my friend on how to carb up and how to hydrate myself sufficiently. I don't think I've ever eaten so many carbs in such a short space of time before!

The morning of the event I, along with hundreds of other people, got on the train from Darlington up to Newcastle. All around me were runners and spectators, the whole atmosphere and friendliness from everyone was infectious. People were so happy and so excited and so keen to be together to embark on such a huge challenge and to complete the half marathon. It took around 2 hours to just to get to the start line – I think I did more than 10,000 steps before I even started the run!



The atmosphere throughout the whole half marathon route was fantastic. People were on the streets clapping and cheering, local bands were playing their music along the route, while the big charities were there supporting their runners.

I must say I enjoyed the run immensely, there was at no point any thoughts about whether I would manage to finish the run in a certain time – it was simply to run every single step. I not only achieved my aim, but I finished the half marathon in 2 hours and 19 minutes – as I crossed the finish line I felt so proud of myself!

If someone had said to me in 2000 that I would be running a half marathon I think I would have just laughed because at that time I was having an acute porphyria attack – I have variegate porphyria (VP). After the attack

I was in the hospital for six weeks, I was unable to walk when I left the hospital and I was having haem arginate four times every week. Unfortunately, this was how my life panned out over the following 7 to 10 years, my porphyria journey was very severe but with the help and support of my family, friends and the experts at Kings College hospital, I have been able to return to running and achieve this huge personal challenge!

Having completed a half marathon, I now have itchy feet and hope to continue my running. I think I will set my next challenge as a full marathon. Who knows, I may well be in the London Marathon in 2023 or 2024.

EVENTS 2023

We are currently planning two events in 2023.

On Sunday 4 June, we're planning an event in the Birmingham area, with support from members from the British and Irish Porphyria Network. The day will include scientific talks/Q&A sessions as well as some patient stories. We hope to hold a social event on the Saturday evening, prior to the main event on the Sunday.

After the amazing success of the Connect Alfresco event, we're planning a similar type of event every two years (Autumn 2023 and 2025). This might take the form of a two-day or residential event, within reach of the M4 corridor in 2023.

Our Events Team is starting to plan both events and will share more details once available, but if you would like to learn more, please keep an eye on our website, or contact us on 0300 30 200 30 or helpline@porphyria.org.uk.

COULD YOU JOIN #TEAMBPA?

If you have just read Kay Bryan's story and feel truly inspired – why not get involved and apply for a place with #TeamBPA in 2023?

The BPA have three places remaining for the prestigious **Virtual London Marathon**. You can walk, run or hike the 26.2 miles from ANYWHERE in the world on **Sunday 23 April 2023**, meaning all 'runners' have 24 hours to track and complete the 26.2 miles!

We also have places available for the world's biggest Half Marathon, the **Great North Run** which is held in the North-East of England on **Sunday 10 September 2023**.

If you are interested or know of someone who has always wanted to set themselves a huge physical challenge, please contact us (helpline@porphyria.org.uk or 0300 30 200 30) ASAP to secure your place and raise awareness and funds for the BPA.



UKPMIS
UK Porphyria Medicines
Information Service

UPDATE FROM UK PORPHYRIA MEDICINES INFORMATION SERVICE

Are you still receiving your annual updated SAFE drugs list from UKPMIS? If not, please contact them on the link below to be added to their database, so that you receive your new copy each year.

Sneezing into Christmas

Flu season is upon us and there is a range of information around about vaccines, treatment, and prevention – but what applies to you and people with acute porphyria?

Vaccinations

If you have an acute porphyria, you can still have the flu vaccine. The flu vaccine is safe and effective and we recommend everyone get it to help stop the spread of flu. We also recommend getting your COVID-19 booster too. Getting vaccinated helps protect those at most risk within the community.

Cold & Flu Remedies

If you do get the flu or a heavy cold, it is important to look after yourself. NHS advice is to:

- Take paracetamol or ibuprofen (both on the Safe-list) if you have a temperature or muscle aches
- Take a decongestant for a blocked nose – both phenylephrine (e.g. Beechams® Cold and Flu Capsules) and pseudoephedrine (e.g. Benylin® Mucus Cough plus Decongestant syrup) are on the safe list
- Rest
- Drink plenty of water

For more information, visit www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/ or call us on 029 2184 2251. If you have any questions, please call us on 029 2184 2251 or visit www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/

JOIN OUR GROWING TEAM

We are seeking an enthusiastic and confident administrator to join us as a Freelance/Self-employed Administrative Assistant.

Location: home based

Expected hours: 20 hours per month – flexible working

Pay: £11.00- £14.00 per hour depending on experience

This is an exciting opportunity to join the BPA and support the team by providing administrative support to the two Strategic Leads. This varied role is the perfect opportunity to develop an understanding of charity administration and fundraising.

Find out more at: <http://porphyria.org.uk/vacancies/>



We're hiring...

Admin Assistant

Requirements

- ✓ Excellent communication skills
- ✓ Superb administrative skills
- ✓ High level of computer literacy
- ✓ Self-driven and motivated

Closing date
31 December 2022



HUGE THANK YOU!

We'd like to thank everyone who has donated and raised funds for the BPA through lots of different ways over the last few months – each and every donation helps with the work we are able to do!

This Autumn saw four #TeamBPA runners in the Great North Run, where Kay Bryan, Danielle Westbury and Kimberley and Sam Gill raised an amazing £2670, while Dr Liezel Griffin, as well as spending time supporting porphyria patients in her porphyria clinic at Salford Royal, also chose to fundraise for the BPA when running the Manchester Half in October, raising a fantastic £985. **THANK**

YOU to all of you for your time and dedication in training and fundraising for the BPA.

In April, Victoria Harrold took on the Yorkshire Three Peaks Challenge. Despite the sun and wind causing an EPP reaction during the walk and during the significant training that went into preparation, Victoria raised an amazing £665 for the BPA. Thank you to Victoria and also to the Mansfield Community Choir who helped raise funds for her challenge as well as supporting Porphyria Awareness Week.

A HEARTFELT THANK YOU and condolences to all those who have raised funds in memory of someone special

– the BPA are very grateful to be thought of in these sad and difficult times. **Thank you** to the family and friends of Margaret Edwards who together raised more than £1,600 in her memory. **Thank you** also to Sally Eyers who made a donation of £600 (after Gift Aid) in memory of her Mum, Ena Eyers. The family and friends of Helen Lane raised more than £1,600 via the funeral directors. **Thank you** to Sandra Norris' family and friends who raised more than £460. Over £200 was also donated in memory of Rose Stevenson – sincere **thank you** to you all.

Harper McDermott sent £200 to the BPA and Ratanben

Gorasin made a donation via JustGiving of £500. Huge thank you to both parties.

We also received contributions of £45 from AmazonSmile and £71 from Easyfundraising. A **huge THANK YOU** to all of you who remember to utilise www.easyfundraising.com and Amazon Smile www.smile.amazon.co.uk, by simply selecting the BPA as your favourite/nominated charity when making online purchases.

Finally, **THANK YOU** to all of you who utilised PayPal Giving Fund over the last few months, collectively raising nearly £50.

CHRISTMAS FUNDRAISERS



This year, the BPA are selling packs of Christmas cards and beautiful glass Christmas baubles to raise funds. 100% of all profits go to the BPA, so you can enjoy sharing these lovely festive items with your friends and family whilst being confident that you are supporting porphyria patients.

Christmas cards

10 cards per pack with two designs in each (five cards of each design). The wording inside each card reads 'Wishing you a Merry Christmas and a Happy New Year'.

- Three packs (30 cards) £10.00 (plus £2.95 p&tp)
- One pack (10 cards) £4.00 (plus p&tp)

Choose from the following options:

- Pack 1: Robin/Hot Chocolate
- Pack 2: Fox/Snowman
- Pack 3: Santa/Bus
- Pack 4: Sheep/Deer
- Pack 5: Geese/Polar Bear
- Pack 6: Hens/Rabbit
- Pack 7: Mixed pack

Christmas bauble fundraiser

The baubles will make wonderful Christmas gifts for friends and family, secret Santa presents, teacher thank you gifts or even table decorations!

- One bauble: Was £6, NOW £4.50 (plus £2.95 p&tp)
- Six baubles: Was £32, NOW £20 (plus £3.50 p&tp)

Choose from:

- Christmas Snowflake Bauble
- Christmas Deer/Tree Bauble

Order directly via eBay www.ebay.co.uk/usr/lizgill_bpa/ or find out more: <http://porphyria.org.uk/christmas-fundraiser/>

We will post orders out immediately until the last Christmas post, but if you're taking advantage of the reduced bauble prices to be super organised for next year, the remaining baubles will be available after Christmas too.

We hope you like the BPA's Christmas fundraiser ideas! We'd also like to take this opportunity to wish you and your loved ones a very Merry Christmas, from all at the BPA.

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
email: 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

Acting Treasurer: Anne Newton

Secretary: Richard Bennett

Strategic Lead of Operations and Advocacy: Liz Gill

Strategic Lead of Engagement and Advocacy: Sue Burrell

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

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.

RAISE FUNDS FOR THE BPA THROUGH EBAY FOR CHARITY

Did you know you can now donate proceeds to the British Porphyria Association? Add the British Porphyria Association as your Favourite charity on eBay.

Purchasing on eBay: You can directly donate to our cause when you purchase goods. Next time you buy from eBay, consider rounding your purchase up in eBay Checkout to support our cause! Every little bit counts. #eBayforcharity

Selling on eBay: You can also sell on eBay and donate some or all of the selling price to charity. You also get a discount on basic selling fees for sold items as they are for charity! What's not to love?

SET UP YOUR LISTING

- Select charity: Choose The British Porphyria Association as your chosen charity
- Select the donation percentage – from 10% to 100%

SELL & DISPATCH

- Item sells
- Buyer pays full amount to seller
- Seller dispatches item to buyer



DONATE

- Approximately 21 days after the transaction is complete, PayPal Giving Fund will automatically collect the donation from the seller
- Once a month PayPal Giving Fund will combine and deliver 100% of all donations collected for that charity

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

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).
- 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 want to Gift Aid my donation and any donations I make in the future or have made in the past 4 years to the British Porphyria Association (Registered Charity No. 1089609). I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all my donations in that tax year it is my responsibility to pay any difference. (I will advise the BPA if my tax status, name or address changes.)

DATE

SIGNATURE