

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



Fundraising in 2025

Looking to get fit or embark on some fundraising for the BPA in 2025?

The BPA have the following event places available in 2025:

- **Brighton Marathon**
Sunday 6 April 2025, 3 places available
- **Great North Run**
Sunday 7 September 2025, 5 places available



Global Porphyria Day – Sunday 18 May 2025

Complete 5K on the 18 May for Global Porphyria Day

Why not organise a local event to raise awareness and fundraise for the BPA on Sunday 18 May? You can set any amount of kilometers, from 1, 2.5, 5, 10 or more and could organise relay events or a local fun run! If you would like to get involved, please reach out and keep an eye on social media too!

Global Porphyria Day Raffle The BPA will be holding a raffle on Sunday 18 May 2025, to raise funds and awareness for the BPA. If you would like to donate a prize or buy tickets, please keep an eye on social media in the New Year, to see how you can get involved!



Other ways to get involved in raising funds for the BPA

- **Easyfundraising:** Why not support the BPA with www.easyfundraising.org.uk! It's so simple: whenever you shop online with over 7,000 retailers, a percentage of what you spend is donated to a cause you care about, at absolutely no extra cost to you. Whether it's your weekly groceries, fashion, or gadgets, your everyday purchases can help make a big difference. Sign up today and start raising funds with every click! Make shopping matter for the BPA, with Easyfundraising.
- **Do you work for an organisation that is keen to support local or national charities?** It can be super easy to engage your employers in fundraising efforts for a charity – and the best bit is that this is a great way to maximise support and create a meaningful impact. Here are some strategies to get employers involved:
 - Charity of the year partnership
 - Matching donations
 - Payroll giving programmes
 - Sponsorships
 - Fundraising events

If the BPA can help support your initiatives in any way, please do reach out: helpline@porphyria.org.uk



ALFRESCO, RESIDENTIAL

THETFORD, NORFOLK, OCTOBER 2024

The BPA held our first Alfresco Residential in October this year for those affected by EPP and XLP. Thanks to protective clothing and the excellent tree cover at Thorpe Woodlands, Norfolk, our adventurers were able to avoid the sun and concentrate on the most important things – connecting with others with porphyria and having fun!

This was our first residential event which built on the success of our day-long event tailored specifically for young people with EPP/XLP and other skin porphyrias back in 2022!

This landmark event for the BPA brought together children, young people, and parents with EPP from across the UK and Ireland, fostering genuine friendships that continue to grow months later. With a weekend full of connection, support, and encouragement, the BPA is proud to have created a unique space to strengthen this vibrant community.

The attendees: In total 52 people attended the event, comprising of:

- 7 x BPA staff/volunteers (3 x EPP)

- 4 x EPP Defenders/volunteers – who were there to support the children and young people with EPP/XLP
- 15 x EPP families/households
- 4 x Videographers (2 x EPP)
- 1 x Counsellor

Structure of the weekend:

Accommodation: The venue enabled families to all stay on-site in glamping style pods or in shared dormitories for the children/young people.

Sun-Safe Activities: The venue and staff were amazing and so supportive of the kids and young people who partook in a full programme of activities, including:

- Caving

- Climbing
- Zip-lines
- Tree-top adventures
- Fan-drops
- Archery
- Team building
- Scavenger hunts
- Fire building and toasting marshmallows

EPP Defenders: The BPA enlisted help from four volunteers: Leah Fearn, Thomas Gill, Lana McGuire, Parker Tapp. All four volunteers were essential throughout the weekend and the BPA is delighted with how they conducted themselves and supported all of the others in attendance – thank you to all four of you, you were real ambassadors to the attendees.



Parent Sessions: Running parallel to the physical activities was a programme for parents and family members which introduced the group to the following:

- BPA Q&A session with Dr Vicky McGuire (BPA Chair), Liz Gill and Sue Burrell (Co-CEOs) and Susie Fearn (our onsite Counsellor)
- Interview with a young adult/film student, Will Fisher – fellow EPPER, who co-filmed/produced (alongside Josiah Iloh) a film that the BPA supported and funded: 'Sol: Living under the sun (2024) - A short documentary. After dinner, we premiered the film to all of the young people and parents – it was very well received by the group. Well done and thank you sincerely to Rosie and James – fellow EPPers for sharing your stories, and to Will and Josiah for executing the most beautiful film which follows these two individuals from very different backgrounds, who are connected by not only their EPP, but also their love for nature! You can checkout the documentary: <https://youtu.be/3kmP5iUwCos?si=B3O9PTx-CNkCcQ9k>
- 1:1 Counselling sessions – Susie Fearn spent most of her time in 1:1 sessions with the parents of young people with

EPP – thank you Susie for supporting the BPA families and communities directly.

- There were ample opportunities for parents and young people to connect with others and build friendships by sharing their experiences.
- Videography team onsite – the BPA enlisted the support of Sam Morrison (EPPER), Kyle Adams and Owen Saddington who volunteered to film and interview attendees to gain insight into the impact of living with EPP as well as documenting the whole event. Thank you so much for being sensitive and nurturing throughout the interviews. The team are currently editing the content, and we look forward to sharing the first video with you, it focuses on a mother and her

son's story and will be shared via our website and social media.

The weekend really was jam-packed – and the BPA feel privileged to have been able to provide this unique space for children and young people with EPP to come together to connect and strengthen our community! We witnessed genuine friendships between the young people, as well as with the parents. The attendees were all willing to try new things and were very encouraging of their new friends. We know that many of these friendships are continuing to develop two months later.

We would like to offer sincere thanks to all those that took part and helped us fundraise to make this happen! As well as our fundraisers, the BPA were awarded support from the National Lottery Community Fund, the Alpkit Foundation, the Society for the Study of Inborn Errors of Metabolism (SSIEM), Mitsubishi Tanabe Pharma Company, Clinuvel Pharmaceuticals LTD, Disc Medicine and Coolibar Sun Protection Clothing – the grants and sponsorship/donations all contributed significantly to making this monumental event possible!

If you'd be interested in potentially attending an event like this in the future, please keep an eye out for updates via social media and future newsletters or email Helpline@porphyria.org.uk to be added to the list of interested parties!

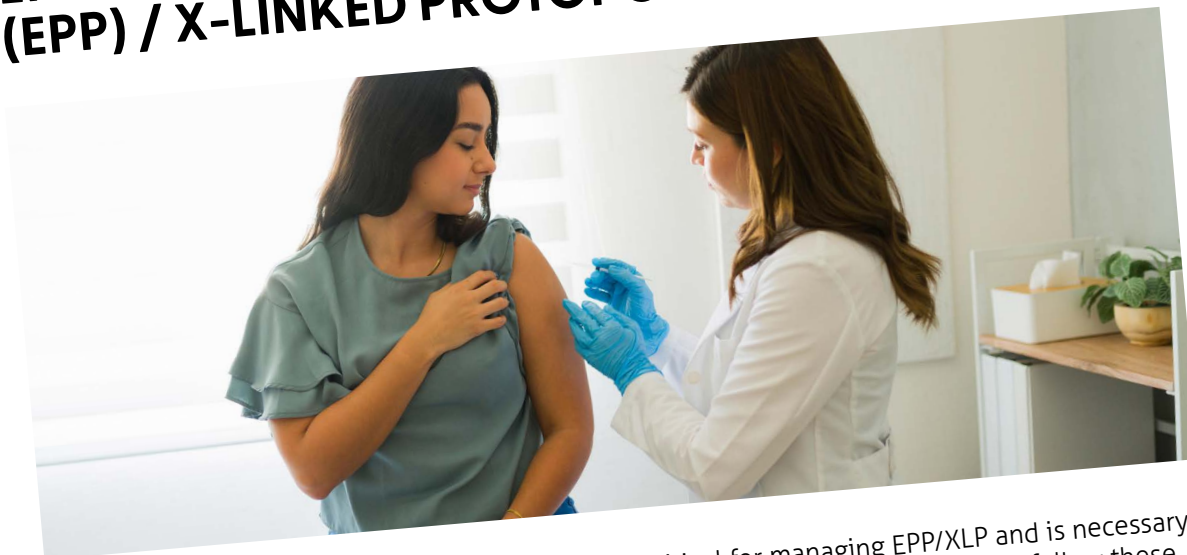




UKPMIS

UK Porphyria Medicines
Information Service

MYTH BUSTERS FOR PATIENTS WITH ERYTHROPOIETIC PROTOPORPHYRIA (EPP) / X-LINKED PROTOPORPHYRIA (XLP)



Prescription Medication

Individuals with EPP or XLP do not need to follow a special "safe drugs" list. Unlike the acute porphyrias, acute attacks are not a feature of EPP/XLP and "safe drug lists" do not need to be adhered to. Some healthcare professionals may confuse EPP/XLP with other types of porphyria and advise against certain medicines inappropriately.

In general, with EPP/XLP you can take any medications your health requires, although, one medication to be cautious about is iron supplements. Always discuss the use of iron supplements or any products containing iron with your porphyria consultant before you start taking them.

Medications and Beauty Products with Sunlight Warnings

Some medications and beauty products recommend avoiding sunlight after use. As EPP/XLP is so rare, we do not have sufficient experience of how these products affect people with EPP/XLP. Individuals with EPP/XLP may be especially sensitive to these effects due to their inherent photosensitivity. Sun protection is

critical for managing EPP/XLP and is necessary throughout life. It's important to follow these sunlight warnings and adopt protective measures, such as using effective sunblocks, wearing sunlight-blocking clothing, and limiting sun exposure.

Most conventional sunscreens primarily protect against UV light and are generally ineffective for EPP/XLP patients, as visible light triggers their phototoxic reactions. Reflective sunscreens containing titanium dioxide or zinc oxide are more effective, as they protect against UVA, UVB, and reflect visible light to some extent. For more details on choosing the best sun protection, refer to the May 2024 BPA Newsletter.

Hormone Replacement Therapy (HRT)

HRT does not need to be avoided in EPP/XLPP. There is no evidence to suggest that HRT poses any specific risks for these conditions, and it can be prescribed without concern. If healthcare professionals require guidance, they can contact the UK Porphyria Medicines Information Service for more information: 029 2184 2251.

HAVE YOU HEARD ABOUT THE NEWBORN SCREENING ‘GENERATION STUDY’?

The Generation Study will sequence the genomes of 100,000 newborn babies which will help to diagnose rare genetic conditions. In partnership with the NHS, it aims to enhance early intervention and care. Developed with input from the public, healthcare professionals, and scientists, it will inform future use of whole genome sequencing in newborn screening.

The study will test newborns for over 200 rare genetic conditions, including: the following porphyrias: erythropoietic protoporphyria and X-linked erythropoietic protoporphyria (EPP and XLP – FECH and ALAS2 genes); variegate porphyria (VP – PPOX gene); congenital erythropoietic porphyria (CEP – UROS gene); and hepatoerythropoietic porphyria (UROD gene).

The test is free, safe and takes place at the routine newborn screening stage, soon after birth. You can learn more about which hospitals are involved in the study and register your interest at generationstudy.co.uk. The website also explains how samples will be collected, how any results will be communicated, the pros and cons of joining the study, as well as other conditions being tested for.

The BPA look forward to hearing more about this research and will share updates once available.



CLINUVEL

disc)medicine



SSIEM



THE BPA AND BETTERHELP ARE PARTNERING TO BRING YOU FREE THERAPY

The BPA has partnered with BetterHelp and BetterHelp Teen Counselling, who have kindly donated to the BPA six months of free therapy to support porphyria patients to start on their wellness journey!

BetterHelp removes the traditional barriers to therapy by providing access that is *convenient* (via video, phone or text) and *tailored* (they match you with a licensed therapist based on your needs, preferences and location).

This is 100% online and will be led by you – it is a completely confidential journey between you and BetterHelp. We are hopeful that the services offered by BetterHelp may work well for those affected by porphyria, due to the convenient and accessible style of therapy offered.

To learn more, please check out our website with more detailed information on how to '[Begin your therapy!](#)'



ICPP 2024: NEWS



Liz, Sue and Vicky represented the BPA at ICPP2024 in Pamplona (Spain) between 21-25 September. It was both a fantastic and exhausting time engaging with the global porphyria community at the biggest International Congress of Porphyrins and Porphyrins yet.

There were excellent talks and posters on topics ranging from porphyria awareness to diagnosis, treatments, patient support and the long-term complications of living with porphyria. There was a real sense of excitement and positivity for the future of porphyria treatments with updates on existing medications as well as newer drugs entering clinical trials.

Treatment of acute porphyrias with Givosiran (Givlaari) was a hot topic. There were lots of discussions around real world usage, and changes in the dose and/or frequency of treatment. Defining breakthrough attacks when on treatment, and clarifying the differences with acute and chronic (long term) symptoms were looked at to help guide when medical

intervention is required. It was also interesting to hear about very early stages of potential new treatments such as CTX450 (CRISPR Therapeutics) a gene-editing therapy targeted to the liver to reduce ALAS1. There were also presentations on the development of computational models to help predict drug safety in the acute porphyrias. The use of genetic BioBank data in the US was shown to be a potential mechanism for identifying undiagnosed individuals with acute porphyrias, whilst the use of country-specific porphyria registry data continues to be valuable in helping to identify long-term complications and propose where new guidance is needed e.g. in the use of hormonal treatments.

The lack of basic testing and treatments in countries without specialist porphyria services was also highlighted; with an estimated 85% of symptomatic individuals living in low/middle income countries without access to diagnosis or treatment, resulting in poor outcomes. Raising awareness of porphyria, especially in these countries, is of utmost importance and an acute porphyria international support group has been established with IPNET to drive this forward.

Hot topics in cutaneous porphyrias included updates on clinical trials: Bitopertin (Disc medicine) was shown to reduce protoporphyrin levels in EPP/XLP resulting in an improved amount of time in light, fewer phototoxic reactions and participants reporting improved quality of life. Bitopertin works to reduce protoporphyrin levels by reducing the amount of glycine available to start haem synthesis in blood cells.

Dersimelagon (Mitsubishi Tanabe) is an oral tablet that acts to increase the amount of pigmentation in skin to protect against the phototoxic effects of protoporphyrin in EPP/XLP. This was also shown to increase time to prodrome and improve patient reported quality of life. However, the clinical trial didn't reach statistical significance at the primary end point (26 weeks) due to strong performance of the placebo group, despite significant changes at other timepoints during the study. As a result, a new phase 3 study (INSPIRE) is now enrolling EPP/XLP patients aged 12+ but is only open to those who have not previously been treated with Dersimelagon.

Encouraging results of a pilot clinical trial of Scenesse (Clinuvel) in 6 adults with Variegate Porphyria skin symptoms showed a reduction in skin symptoms and improved quality of life with implants every 28 days for 6 months and will potentially lead to a larger clinical trial.

Left to right: Dr Vicky McGuire (BPA Chair), Liz Gill (BPA Co-CEO) and Sue Burrell (BPA Co-CEO)





PORT-77 (Portal Therapeutics) was introduced as a potential new treatment for EPP/XLP in early stages of clinical trials. It acts to keep protoporphyrin within blood cells to prevent it being transported to plasma and skin where it could cause phototoxic reactions. It is currently in phase 1 healthy volunteer studies, with early data suggesting it is well tolerated and could be available for oral administration.

ATL-001 (Atlas Molecular Pharma) was introduced as a potential new treatment for CEP which works to stabilise the enzyme affected and allow it to work more efficiently. A phase 1 trial has been completed with no issues noted and the terms

of a phase 2 trial have been agreed with the FDA to recruit 6 individuals with CEP, with an aim to start in spring 2025.

The importance of addressing vitamin D deficiency to prevent osteoporosis in EPP was emphasised, as well as recommending DEXAscan methods to monitor bone health and FibroScan to monitor liver fibrosis in EPP.

Abstracts for the poster presentations can be found here:
https://bmjopengastro.bmj.com/content/11/Suppl_1

Link to the special edition of Liver International Journal:
[https://onlinelibrary.wiley.com/doi/toc/10.1111/\(ISSN\)1478-3231.porphyrins-and-porphyrrias](https://onlinelibrary.wiley.com/doi/toc/10.1111/(ISSN)1478-3231.porphyrins-and-porphyrrias)

BPA ICPP 2024 UPDATE

Patient Sessions

The Congress started with a **Patient's Day in Spanish** (Saturday), followed by a **Doctor and Patient Workshop** – formerly known as the Patient Day (Sunday). The 'patient' was placed at the centre of the content which included updates on potential new medications for the porphyrias, as well as hearing eloquently from various patients from Spain and around the world! It was inspiring to hear from these brave patients and their families who willingly exposed their vulnerabilities and shared their stories. One of the most salient talks from the two days was from a teenager from Germany, with EPP. Laura beautifully shared, via video, her story which resonated profoundly, inspiring others in the room and online, including medical and scientific

faculty members, and importantly the pharmaceutical companies researching into potential new treatments for EPP! The whole porphyria patient community (patients, family members and Patient Advocacy Group leaders) were listening, too!

Patient Advocacy Group (PAG) Leader's Meeting

The Global Porphyria Advocacy Coalition (GPAC) held a 4-hour meeting, including their AGM, and discussions of global advocacy strategies and plans for the next two years. In addition to Patient Advocacy Group leaders in attendance, pharma representatives joined part of the meeting to engage in candid and open Q&A sessions where the needs of patients across the globe were discussed and championed.



GPAC and PAG Leaders: ICPP, Pamplona, 2024



IN MEMORY

The BPA would like to extend our heartfelt thanks for your generous legacy donation of £10,000 from Margaret Theresa Seary – known as 'Peggy' to her friends and family.

'Peggy' lived in Lancing, West Sussex, having previously lived in Peckham SE London, she was originally from Wexford, Ireland, moving to England when she was 8 yrs old. She was one of 10 children and had 5 brothers and 4 sisters. Peggy had AIP and has been a long supporter of the BPA. She had been so pleased to find the BPA and support the work we do for the porphyrias. Her family believe that she was diagnosed in London in her late teens; unfortunately, her ill health never enabled her to attend any of our face-to-face meetings.

We are deeply touched by the generosity of Peggy and her two children – Donna and Jason, and their respective children – Lewis and Ellis, for thinking of the BPA with such a meaningful act of kindness.

This donation will honour Peggy by continuing to make a huge difference to the work the BPA can do and will positively support future generations impacted by porphyria!

Thank you again for this generosity and for keeping Peggy's memory alive in such a profound way!

Leaving a legacy donation

If you or a family member would like to consider leaving a legacy donation to the BPA, you can read more on how to do this on our website: <http://porphyria.org.uk/donate/>

THANK YOU TO CLINUVEL LTD

The BPA would like to take this opportunity to say a HUGE thank you to CLINUVEL PHARMACEUTICALS LTD, on behalf of the porphyria community. CLINUVEL very generously and kindly donated over 400 bottles of the CYACËLLE Polychromatic Solar Protection large particle sun cream (in two different batches) which have helped so many skin porphyria patients in the UK and Ireland since July. This summer has been especially tricky as there are currently no sun protection options available to patients with EPP/XLP on prescription!

Don't forget, if you haven't already, please share your thoughts on the cream, by completing the survey so that we can share feedback with regards to how successful CYACËLLE has been for porphyria patients who experience phototoxic/photosensitive reactions:

<https://forms.office.com/e/YjYj4BmpLJ>

If you have EPP/XLP, CEP, PCT, HCP or VP and would like an additional bottle of Cyacëlle, or didn't get one sent the first time, we still have a few remaining and would be very happy to send one out to you. Please contact kathryn.wilson@porphyria.org.uk and she will discuss the next steps with you.

Thank you again to CLINUVEL, from the BPA and the skin porphyria community!



CARDIFF MEETING 2025

The BPA are pleased to announce our next patient event will take place on **Saturday 29 March 2025** at the **National Museum of Wales, Cardiff**.

All are welcome; patients, their families/friends, and medical professionals alike. The programme will include doctor and patient talks, question and answer sessions, updates on research and a final social session providing plenty of opportunities to connect and share with other patients.

Full programme TBC – for now please register your interest and save the date!



Please note: We are introducing a small charge of £5 per person for attending all future patient events, in the hope that we can reduce the costs incurred when participants who register do not attend. We can provide a refund on any cancellations made by 15 March 2025. Thank you for your understanding.

Accessibility: the BPA are keen to ensure that our events remain fully inclusive and accessible to all so if you feel unable to pay the £5 registration fee, please contact us. We also have a number of travel bursaries available for those who would be unable to attend without our support. Please contact helpline@porphyria.org.uk to discuss further.

Register: Please register your attendance here: <https://buytickets.at/thebritishporphyriaassociation>



SAVE THE DATE



**National Museum of
Wales, Cardiff**

Saturday 29 March 2025



SCENESSE® RECEIVES EUROPEAN ORPHAN DRUG DESIGNATION FOR VARIEGATE PORPHYRIA

Clinuvel's treatment, SCENESSE® (afamelanotide), has received a positive opinion for an orphan drug designation (ODD) from the European Medicines Agency (EMA) for the treatment of variegate porphyria (VP).

The Committee for Orphan Medicinal Products (COMP) recognised the chronically severe nature of skin symptoms in VP, the high unmet need, lack of alternative therapies, and afamelanotide's potential as a VP treatment. The clinical evidence revealed from an open-label six-month study of six adult VP patients was considered to be a sufficient proof-of-concept to enable a positive opinion.

What does this mean for patients? Orphan drug designation is a means to ensure that rare conditions, often overlooked by drug developers, receive dedicated research and attention. Medicines with ODD may benefit from accelerated approval processes, financial incentives and scientific advice for further development.

Achieving ODD is a significant step along the very long regulatory pathway to extend the existing approved label for SCENESSE® to include VP. So although this may be a long process, we will keep you updated of any new developments as we hear them.

THANK YOU

We're thrilled to celebrate some of our amazing community members who have gone above and beyond to make a difference through their incredible fundraising efforts. Every step, every mile, and every roll of the dice has helped support our mission, and we couldn't be more grateful. Here's a huge shout-out to some recent fundraisers.

Great North Run superstars: A massive thank you goes out to our incredible Great North Run participants! Running 13.1 miles is no small feat, and we're beyond proud of John Critchley, Becky Lines, Anna-May Livingstone, Jack Livingstone and Carly Brearley, who collectively raised over £2,300 for the BPA! Your endurance, dedication, and community spirit truly inspire us all. Every penny raised will go directly towards supporting our projects and services. Thank you for lacing up your shoes and going the extra mile (or thirteen!) for us.

Family fun run champions: The O'Keefe family also deserve a big round of applause! This wonderful group put their best feet forward, raising a whopping



£1,320 through the Royal Sutton Fun Run. Shea ran 8.5 miles in 1 hour 35 and Connie aged 7 came in 20 minutes later! It's incredible to see families coming together to make a positive impact. Thank you for your dedication to helping us continue our work and for showing that making a difference can be a family affair.

We'd also like to extend a special thanks to Karen and her friends at the Wheathill Golf Club who have been fundraising for nearly a year. They have hosted various activities including a Race Night and a fantastic golf tournament, raising an impressive £3,000 at the last count, with the amount still growing! The event was a true success, with everyone showing both skill and generosity on the green. We're very grateful for your commitment to our cause.

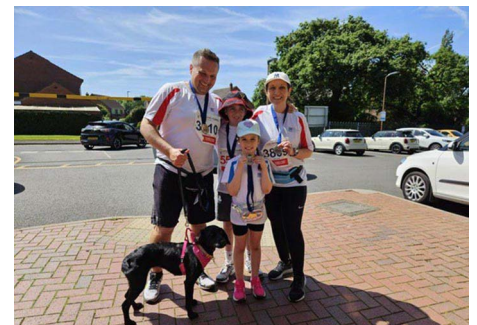
Kilt Walk Warriors: Two dedicated walkers, Matthew Robb and Nicki Traynor, proudly donned their kilts and raised £944 to support our mission. Thank you both for

embracing the spirit of the Kilt Walk and for your generous contribution.

In support of our Empowering Porphyria Patients campaign, Coterie Creative sent a very kind donation of £250, Victoria Harrold raised a fantastic £218 by taking the time to do a birthday fundraiser, Karen Harris raised £145 at a coffee and cake morning, Oran Carlin and his family raised over £2,700 climbing Mount Errigle in County Donegal in September, Natassja Chadwick and her friends and family continued fundraising too! Thank you all for your support with this campaign.

Nikki Rutter set up a wonderfully creative 'stupid things I do while at work' page to raise funds to help us continue our work. Thank you, Nikki for your 'wholesome swear jar' approach to fundraising. We love this idea!

Duke of Edinburgh (DofE) volunteers' Dungeons and Dragons fundraiser: Last but definitely not least, we want to



celebrate Parker Tapp, a Duke of Edinburgh volunteer who hosted an adventurous and entertaining Dungeons and Dragons evening. With creativity and a bit of magic, he raised £147 to support our projects. Thank you for bringing a touch of fantasy to fundraising—your imagination and hard work made a real impact. Tanya Sharma and Agnivo Chowdhury also ran a Christmas fundraiser stall at their school, as part of their DoFE volunteering, to raise funds for the BPA. Tanya went on to successfully sell lots of baubles to her family and friends too – thank you all for your hard work and awareness efforts within your local community.

Thank you to all of our incredible fundraisers for their time, energy, and generosity. Because of you, we're able to make a difference in the lives of those we support. We're proud to have such passionate and creative people in our community.



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.

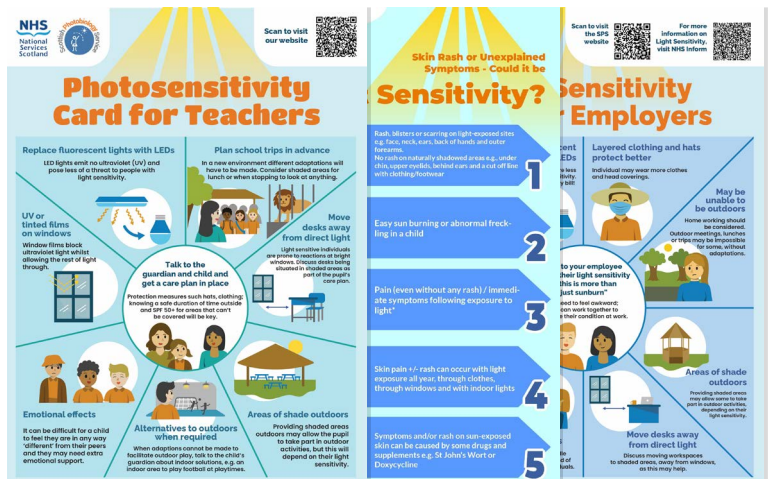
Please leave your name, phone number, day and time of message and someone will call you back as soon as possible.

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.

- Chair:** Dr Vicky McGuire
Treasurer: Claire Jarvis
Secretary: Victoria Harrold
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Co-CEO: Sue Burrell
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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.



SUPPORT IN THE WORKPLACE FROM THE PHOTOBIOLOGY SERVICE NHS SCOTLAND

We are pleased to share three helpful new factsheets on light sensitivity created by the Scottish Photobiology Service:

- Teacher's Information Card
- Employer's Information Card
- Red Flags Card for GPs

These factsheets have been created in collaboration with light-sensitive patients to help you advocate for #Porphyria

awareness with your school, employer and healthcare practitioners.

They provide comprehensive information about light sensitivity conditions to help you navigate difficult conversations about your care and remind others about access needs which might be invisible.

Download the factsheets today at porphyria.org.uk/factsheets.

THE BRITISH PORPHYRIA ASSOCIATION Registered Charity No. 1089609

MEMBERSHIP / DONATION FORM



MEMBER DETAILS

Please complete (*required field) and return to:
BPA Treasurer, 69 Cannell Road, Loddon, Norwich, Norfolk, NR14 6TP
 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