

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



SUNSCREENS

Many of you will be aware that there have been supply issues with Dundee Cream caused by a lack of access to a key ingredient.



This week, we learned that production has stopped, and patients are unable to access Dundee Cream at all. We are working to find other options for patients to be able to ask for on prescription, but in the meantime, there are some other sunscreens available to purchase which may provide some relief.

A reminder that when searching for sunscreens, mineral sunscreens containing zinc oxide and/or titanium dioxide offer some level of protection by providing a physical block to visible light. Generally, the larger the particle size, the greater the protection. So the creams that offer the greatest protection are likely to be thicker, messier and quite opaque.

Of the alternatives noted below – the top two* have been shown by a study (see below*) to be at least as effective as Dundee Cream and in some colours, even more so.

- Anthelios Mineral One (light, medium, tan, brown and dark brown), La Roche-Posay*
- Anthelios Pigment Correct, La Roche-Posay*
- Surf Mud natural zinc
- Invisible Zinc Broad Spectrum 50 SPF
- Neutrogena Sheer Zinc-Oxide Face dry-touch sunscreen 50 SPF
- Cyacelle 50+ UVA/UVB/HEV large spectrum protection

It is important when purchasing the Anthelios Mineral One cream that the correct versions are bought, as we have discovered that there are many different formulations, and as yet, we don't know how effective they may be in comparison to those already tested.

The images might be useful to you in any search.

*Ewan Eadie, Martin Josso, Rita Touti, Pascale Renoux, Robert S Dawe, Sally H Ibbotson, Commercial visible-light protecting sunscreens for photosensitive individuals, British Journal of Dermatology, Volume 188, Issue 3, March 2023, Pages 445–447, <https://doi.org/10.1093/bjd/ljac112>

BPA RECONNECT - DUBLIN, IRELAND SUNDAY 3 MARCH 2024

We were pleased to return to the Ashling Hotel, Dublin on Sunday 3 March 2024, for a much needed patient event in Ireland. This event was organised with the support of the team at St James's Hospital, Dublin and the British and Irish Porphyria Network (BIPNET). In attendance was a mix of patients, their families/friends, and medical professionals.

The programme included 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.

A HEARTFELT THANK YOU

Recent years have tested our financial resilience, and our reserves during the 2023 year sank lower than for many years. The COVID-19 pandemic had a profound knock-on effect on our fundraising efforts, limiting our ability to generate income, and the ongoing cost of living crisis has added another layer of complexity to our fundraising.

In the face of such challenges, we are immensely grateful for the unwavering support of the following amazing organisations and wonderful fundraisers.

FULFILLING OUR MISSION WITH THE SUPPORT OF THE NATIONAL LOTTERY COMMUNITY FUND AND OTHER PARTNERS

We have recently been awarded a series of grants and sponsorships which will be instrumental in helping us realise our strategic aims for 2024 and get us back on track.

Their contributions have allowed us to continue our vital work, providing invaluable support to patients and their families when they need it most. Whether it's helping to gain access to treatments, providing opportunities to improve mental and physical wellbeing, or providing much-needed helpline and advocacy services, their generosity has a tangible and life-changing impact.

The National Lottery Community Fund, Alpkit Foundation, Alnylam Pharmaceuticals, Clinuvel Pharmaceuticals Ltd, Disc Medicine, Mitsubishi Tanabe Pharma America and the Society for the Study of Inborn Errors of Metabolism (SSIEM) have provided support this year. Their grants and sponsorships will contribute towards some of the following projects in 2024, as well as ensuring that we can still be here to advocate for all porphyria patients through all our usual channels.

- Enabling the BPA and BIPNET (The British & Irish Porphyria Network – a clinician-led best practice network), to collaborate to host a much-needed Patient Day and BIPNET Annual Conference in Dublin in March 2024.
- Raising awareness of the porphyrias through campaigns around Rare Disease Day and Global Porphyria Day.
- Contributing to the Alfresco Residential – an activity weekend designed especially for young EPP patients. A project that aims to remove barriers to being in nature and enable our EPP community to experience the mental and physical benefits of being outdoors, while learning strategies to manage their condition.

Clinuvel Pharmaceuticals Ltd also sent the BPA a number of CYACELLE sunscreen products for EPP patients to test and feedback on. THANK YOU for supporting EPP patients.

We would also like to say a HUGE THANK YOU to Daniel Wentzell and his team at Coterie Creative who continue to donate their time, expertise and publishing know-how to generate such wonderful Newsletter publications for the BPA, completely free of charge. We are extremely grateful for Daniel's continued support!



ANNOUNCING OUR NEW TREASURER: A WARM WELCOME TO CLAIRE!

We are thrilled to announce a significant transition within the BPA. Claire Jarvis, who has been an invaluable volunteer for the past year, has graciously accepted the role of treasurer. We are extremely grateful to Claire for stepping into this essential voluntary position, and we warmly welcome her to her new role.

Claire's dedication and commitment to our cause have been evident throughout her time as a volunteer. Her skills and diligence make her the perfect fit for the role of treasurer. We are confident that under her guidance, our financial affairs will be managed with utmost care and efficiency.

As we welcome Claire, we also want to express immense appreciation to Anne Newton, who has served as our treasurer for approximately 15 years. Anne's time as treasurer has been marked by integrity and a genuine commitment to the BPA's cause and we are immensely grateful for all she has done over the years.

So, CONGRATULATIONS Claire, on your new role, and THANK YOU, Anne, for your extended time as treasurer.



THANK YOU TO OUR COMMUNITY OF FUNDRAISERS

Fundraising by our community is the lifeblood of our organisation, fuelling our ability to provide vital support and services to those in need. It's through the generosity and compassion of individuals that we are able to make a real difference in the lives of patients and their families.

Some recent fundraising for the BPA has been particularly impressive.



Alyx Byrne and Natassja Chadwick held a Bingo night and raffle, sourcing some amazing prizes from their generous local community. They raised a whopping £1,300. THANK YOU, Alyx and Natassja! Thank you also to the team of volunteers who supported them and the local businesses who supported their venture. Amazing!

THANK YOU to Karen Harris and specifically Anne Scott, the current Ladies Captain at Wheathill Golf Club. The local Brue Valley Rotary Club (John Holt, Rotary Club President) jointly hosted a Race Night with Wheathill Golf Club which raised over £1,200. To date, they've raised over £1,769! This is amazing, THANK YOU to Anne and all your friends from the Club for your support to the BPA. We wish you the very best of luck in your remaining fundraising initiatives at the Club in 2024!

Read about Lana's incredible dedication and the success of her fundraising event, at her school, which exemplifies the power of community-driven initiatives. With her remarkable efforts, Lana has not only raised funds

but also inspired others to join our cause, creating a ripple effect of kindness and support that reaches far beyond her school walls. THANK YOU, LANA! We are immensely grateful for Lana's passion and commitment, and we look forward to continuing our journey together as we strive to make a meaningful impact in the lives of those we serve.

Duke of Edinburgh (DofE) – the BPA have just taken on three DofE Gold Award volunteers who will be fundraising for and supporting the BPA over the next 12 months. If you know of any students from your community who are looking for voluntary work, please reach out to the BPA, as we may be a great fit for them. We wish Agnivo, Parker and Tanya, from Kent, the best of luck with their awareness activities, fundraising and volunteering with the BPA.

Finally, the BPA would like to offer a sincere THANK YOU to the family and friends of Roisin (Rosie) Bradley. In tribute to Rosie, your generous and kind donations have raised over £225 (so far). THANK YOU for thinking of the BPA at this very sad time.

GET INSPIRED BY LANA'S FUNDRAISING ACTIVITIES FOR RARE DISEASE DAY, 2024!

I was inspired to volunteer and fundraise for the BPA after attending the first Connect Alfresco event in 2022 where I met a fabulous group of children who were determined to have as much fun as possible despite the challenges of EPP. I set about organising a non-uniform fundraiser at my school on Rare Disease Day (29th February) using the Purple for Porphyria campaign. I started by contacting my head teacher, explaining about the Connect Alfresco 2024 Residential and how important I thought it was to support children with EPP to be able to participate in the activity weekend. My school were really supportive and the date was put in the diary for a non-uniform day. To raise awareness beforehand and to explain what the fundraiser was for, I gave a presentation during assembly about porphyria and the challenges faced by people who have porphyria. I encouraged everyone to bring a £2 donation and wear purple if they could. As most of my friends

didn't have anything purple to wear, I decided to sell purple ribbons as another way to raise awareness and money. We bought 100 ribbons online, and in the week leading up to Rare Disease Day I visited individual tutor groups in my school to promote the campaign and sell ribbons, as well as answering any questions people had about porphyria. My parents also sold ribbons at work and we soon sold out!

I'm still amazed at how successful the fundraiser was – the total raised was £607.12 – and I am really proud that I have helped to increase awareness about these rare diseases. Almost my entire school participated in the day and contributed generously. I was really nervous talking about porphyria to start with, especially to such big audiences, but each time I explained what it was, how to pronounce it (!) and how important it was for children with EPP to have this kind of opportunity, my confidence grew and I



was really happy to hear people talking about porphyria. I am really grateful for all the support I had from my school, family and friends and I am very proud of everything we achieved together.

The Purple for Porphyria information on the BPA website was great and really helped me with my campaign. I hope this will help and inspire you to fundraise for the BPA and raise awareness for EPP, as the more people who know about porphyria the better!

Written by Lana McGuire

EXCITING VOLUNTEER OPPORTUNITIES

Would you like to make a positive impact to the porphyria community by volunteering just 4-5 hours a month (roughly an hour a week!)? Look no further! We're seeking some volunteers with specific skills to join us in making a meaningful difference to others.

Admin support volunteer: are you digitally savvy and would be happy to support our admin team by sending out information and merchandise to members?

Social giving volunteer: are you a digital native with prior success in creating compelling stories and campaigns on social media? Help us explore ways for donors to give virtually and in-channel on social networks, such as TikTok and Instagram.

Volunteer legal advisor: do you have legal experience and can you guide us on a variety of topics, such as checking contracts (on an ad-hoc basis)?

Trustee for fundraising: we are looking for someone to strengthen our Trustee Board skill set. The ideal candidate will have strategic experience in fundraising or bid writing.

We're an enthusiastic team who have a passion for supporting those affected by porphyria. Join us today to be part of something truly meaningful. Whether you have an hour or so to spare each week or want to commit to more, we'll be delighted to hear from you. *Learn more* about the roles on our website.



PORPHYRIA AWARENESS WEEK 11-18 MAY 2024

GLOBAL PORPHYRIA DAY – 18 MAY 2024!

This year the BPA will be celebrating Global Porphyria Day (GPD) on the 18th May! Porphyria patients and their families from around the world will be getting involved in the week of the 11-18th May to engage in awareness and fundraising activities to share insight into **#MyPorphyria**.

Our website has some amazing resources that you can use to organise an awareness/fundraising event. Get involved to help us to **#SpotlightPorphyria**.

Why not join us by organising a **#PurpleForPorphyria** day at your school or workplace? Ask people to wear purple and donate £1 or £2 to the BPA. You can find a toolkit of resources to help you take part on our website, including template letters and posters.



PEER SUPPORT DROP-IN SESSIONS

We were delighted to welcome a group of BPA members with EPP/XLP and other skin porphyrias to our first ever online Peer Support Drop-In session in March.

We know how isolating it can feel to live with a rare disease. We also know how much knowledge and expertise is contained within each and every person with a rare disease. That's why we want to bring together people with EPP/XLP and other skin porphyrias, and their families and friends, to share experiences, challenges, and coping strategies for living with porphyria.

The BPA's new Peer Support Programme offers porphyria patients, as well as their family and friends, a safe and welcoming online space where you can join others with EPP to chat about challenges and gain tips on things that have worked for others. The programme aims to help people living with porphyria

to **understand** their condition, **connect** with others, build the confidence to **take control**, and **share** their story.

The sessions are open to all ages, and families affected are encouraged to attend together. You're warmly invited to **save the dates** and **register** (via the BPA's *Events page*) for our next Peer Support Drop-In sessions, taking place online on:

- **24 June 2024**
- **30 September 2024**





BPA CONNECT ALFRESCO 12-13 OCTOBER 2024

We are in the final stages of booking children, families and young people onto our sun-safe Connect Alfresco event! The activity weekend will empower young people with EPP to **understand** their condition, **connect** with others, build the confidence to **take control**, and **share** their story.

The event is a 1 night residential to be held at the *Thorpe Woodland Activity Centre* in Thetford, Norfolk. Attendees will arrive on the Saturday morning and depart after lunch on the Sunday. The two days will be filled with amazing outdoor activities for our EPP community.

The venue has flexible accommodation options: young people/children will be able to stay in indoor dormitories with friends of similar ages, or in family pods (outdoor wooden cabins – short outdoor walk to toilet/shower block).

If you are still interested in attending and haven't completed your booking form, please reach out urgently to sue.burrell@porphyria.org.uk and we will arrange a call to discuss further. We only have a few places left and will be offering any remaining places to our EPP friends and families from overseas to join us in October.

DATES FOR YOUR CALENDAR

Peer support drop-in online sessions

24 June 2024

30 September 2024

International Congress on Porphyrins and Porphyria (ICPP)

Pamplona, Spain

21-25 September 2024

BPA Connect Alfresco

Thetford, Norfolk

12-13 October 2024

BPA Connect

Cardiff

March, 2025

ACCESS CARDS

Would you like to visit an attraction, such as a theme park, but don't feel that this is achievable due to your porphyria? Access Cards offer increased accessibility to thousands of UK attractions, venues, and events for individuals facing challenges due to disabilities, including porphyria.

What is an Access Card?

An Access Card is available for anyone who meets the criteria for being a disabled person, as defined by the Equality Act. For anyone who's life is impacted by EPP, or an acute porphyria (that has a substantial and long-term impact on them), it is likely that they will be eligible for an Access Card!

The card, valid for three years at a cost of £15, clearly communicates access requirements and the barriers you face with personalised symbols, such as the need for a companion or an inability to stand in queues. You may have other health/access needs that can be identified and reflected by some of the other symbols. It contains your photograph and is effectively a disability passport that informs providers of your needs quickly and discretely.

Applying for an Access Card – what do you need?

Ideally, you should provide as much evidence as possible when applying for the Card, so have all of this ready before you start the application. You are likely to need:

- Photo ID or (for a child/young person) a photo and birth certificate
- Proof of address
- A letter from your specialist or doctor confirming your diagnosis (such as EPP or acute porphyria) hopefully with some information about the impact that your condition has on you
- Any other evidence such as Disability Living Allowance (DLA) or Personal Independent Payments (PIP) and why this has been provided
- You will need to provide brief explanations* for why you feel you need each of the symbols on the Access Card
- A supporting letter from the BPA*

*Please contact the BPA on helpline@porphyria.org.uk if you would like a supporting letter and some sample explanations/standard responses that may be helpful for your submission.



Remember, the BPA can help with information/evidence and we can even support you completing the application, if needed. The BPA can also help to cover the cost of the Access Card, for anyone needing additional support. Just reach out to us: helpline@porphyria.org.uk



UKPMIS

UK Porphyria Medicines
Information Service

USING HORMONE REPLACEMENT THERAPY (HRT) IN PORPHYRIA

An update from UK Porphyria Medicines Information Service

In this and upcoming newsletters we are going to be talking about the use of hormone replacement therapy in those with porphyria. This month we're discussing the use of hormone replacement therapy (HRT) in those with an acute porphyria.

HRT and acute attacks

Some people with an acute porphyria (acute intermittent porphyria, variegate porphyria or hereditary coproporphyria) are at risk of developing acute attacks of porphyria. These usually start with pain in the abdomen, back or thighs. Nausea, vomiting and constipation are also common symptoms. These episodes can be very severe and often require hospitalisation.

Acute attacks can be triggered by a number of different factors including medications, alcohol, fasting, hormones especially progesterone, illness and stress. There is a higher risk of developing an acute attack if you:

- have a history of previous acute attacks
- are aged from late teens to early forties
- are female

As women go through menopause, their ovarian function decreases and the hormones oestrogen and progesterone fall to low levels. Hormone replacement therapy simply replaces these hormones, which helps to reduce menopause symptoms. Sometimes HRT is also used in young women with certain medical conditions.

If you have an acute porphyria, be aware that HRT may trigger an acute attack. Only start HRT with the support of a medical professional.

Oestrogen and progesterone

HRT can contain oestrogen alone or in combination with progesterone. Although both oestrogen and progesterone are thought to trigger acute attacks, oestrogen is thought to be less likely to trigger an acute attack than progesterone.

It is often possible to avoid hormones and treat the symptoms of the menopause individually with medications from the safe drug list. If HRT cannot

be avoided then medications without progesterone are preferred. This approach however usually then requires additional follow up and monitoring.

Topical treatments (e.g. gels and creams) are usually considered safer than oral (e.g. tablets) treatments. This is because less of the medicine is absorbed into the blood when put on the skin.



Precautions to take when prescribed HRT

If you have an acute porphyria and are prescribed HRT, make sure you:

- have reminded the health care professional that you have an acute porphyria
- are taking the lowest possible dose to manage your symptoms
- never have a hormonal implant or injection as these cannot be taken out if an acute attack occurs
- stop the HRT and report to your specialist if you get symptoms of an acute attack, such as abdominal pain

The information here is not exhaustive and is specifically for patients with an acute porphyria. For more information about HRT treatment and acute porphyria speak to your healthcare provider or call us on 029 2184 2251.

For more information on acute porphyria and SAFE medications, visit www.wmic.wales.nhs.uk/specialist-services/drugs-in-porphyria/ or call us on 029 2184 2251.

Are you still receiving your annual SAFE drugs list? If not, please call us on 029 2184 2251.

EMPOWERING PORPHYRIA PATIENTS

This year, the BPA is concentrating its fundraising efforts on one clear goal, to **Empower Porphyria Patients**. Our main event associated with this is the BPA Connect Alfresco on the 12-13 October 2024!

Could you help us raise funds?

We are running a huge fundraising drive that will, among other things, enable us to support the Alfresco residential activity weekend in October, enabling children and young people with EPP to safely experience the mental and physical benefits of the great outdoors – and, we need your help to

reach our £20,000 target. There are so many different ways to *fundraise* for the BPA and contribute to the Alfresco project.

Check out Lana's fundraising story for ideas on fundraising!

The BPA website has a whole host of tools available to get you involved in fundraising for the BPA: porphyria.org.uk/fundraising.

Can't organise an event this time, but want to donate instead?

If you're not able to organise an event, you can always make a donation in honour of **Rare Disease Day, Porphyria Awareness Week, or Global Porphyria Day (or any other time of year!)**.

You can sign up to make a regular monthly donation or opt for a one-off payment – every little helps achieve our goal of supporting people affected by porphyria and their families.



HELP US RAISE £20,000

GETTING INVOLVED WITH RESEARCH

There's a lot of research going on in the porphyria world at the minute, especially with regard to EPP, so we wanted to share a little about how you might be able to get involved in different types of research, should the opportunities arise.

Jumping into research studies and clinical trials can be a game-changer for patients, especially those dealing with rare conditions like porphyria, where we face tough battles with limited treatment options and not enough knowledge about how our quality of life is affected.

Being involved in research can take various forms:

- Clinical trials stand out at the forefront of research, testing new treatments or therapies for safety and effectiveness. These trials often include phases such as testing on small groups of individuals (Phase I), to larger populations (Phase II and III), before potential approval.
- Quality of life studies delve into the everyday impact of diseases or treatments on patients' well-being, providing valuable insights into how to improve overall quality of life.
- Market research plays a crucial role in understanding patient preferences, needs, and challenges, aiding in the development and distribution of healthcare products and services tailored to patient needs. These diverse research types collectively advance medical knowledge and enhance patient care.

One big perk of joining studies is being in-the-know about new treatments or therapies that aren't available through regular channels yet. It's like being on the VIP list for medical breakthroughs! By getting involved, patients help scientists understand more and pave the way for better treatments, not just for themselves but for others in the same boat.

To learn more about research trials and studies, we recommend being connected to a porphyria specialist centre or a photobiology/photodermatology specialist. That's where all the action is! As well as hearing about new developments through the BPA, being connected to these centres means hearing about chances to be part of something big and potentially life-changing.

Get involved!

1. Contact helpline@porphyria.org.uk to let us know about your willingness to be involved in research.
2. Find a specialist centre close to you porphyria.org.uk/expert-contacts/

Joining research studies and clinical trials isn't just about helping yourself – it's about helping others and being a driving force behind the next big medical breakthrough.

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.

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Secretary: Richard Bennett

Strategic Lead of Operations and Advocacy: Liz Gill

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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.

WE'RE TAKING PART IN THE BIG HELP OUT – THE UK'S BIGGEST EVER MASS VOLUNTEERING MOVEMENT FROM FRIDAY 7TH - SUNDAY 9TH JUNE 2024.

In 2023, 7.2 million people took part in the Big Help Out during the King's Coronation weekend — lending a hand and making a difference in their local communities. We're joining hundreds of the UK's most trusted organisations and invite you to:



- 1 Save the Date
- 2 Pledge to Volunteer! Be it a day or an hour, pledge to make a difference at www.thebighelpout.org.uk
- 3 Spread the word on Socials!
**"I'm joining #TheBigHelpOut from 7-9th June 2024!
Get involved too at thebighelpout.org.uk"**

Let's make 7-9th June the biggest volunteering weekend ever.

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