

THE BRITISH PORPHYRIA ASSOCIATION NEWSLETTER

Registered Charity No. 1089609



"Since high porphyrin levels cause acute attacks, it may be possible to suppress an attack by partially blocking the production of the RNA which helps build ALAS1."

ALNYLAM PHARMACEUTICALS: DEVELOPMENT OF POSSIBLE TREATMENT FOR ACUTE PORPHYRIA

Alnylam is a growing biotechnology company in Cambridge, Massachusetts, USA. They are developing small interfering RNAs (siRNAs) to treat several conditions. This uses a natural process which controls the production of proteins in cells. While DNA is the chemical in cells that forms our genes, it has to be copied to produce proteins. RNA is the messenger that cells use to carry the code from the genes. siRNAs block the ability of RNA to make the relevant proteins.

In acute attacks, an enzyme (protein) at the beginning of the haem building sequence, ALAS1, is known to increase. So it increases porphyrin production. Since

high porphyrin levels cause acute attacks, it may be possible to suppress an attack by partially blocking the production of the RNA which helps build ALAS1. (See our Introduction leaflet and website, for more detail on the haem synthesis process.) So, Alnylam are developing an siRNA to do this, known as ALN-AS1.

They will start with the **explore** study to better understand porphyria and plan future tests. **They are asking for volunteers in the UK** via Kings College Hospital and University of Wales Hospital, Cardiff, as well as collaborating with NAPS. If you would like to take part, please contact the BPA on 0300 30 200 30, or helpline@porphyria.org.uk and

we will send you more information about whether you fit the study criteria. Then the researchers will select an appropriate range of people from across the world.

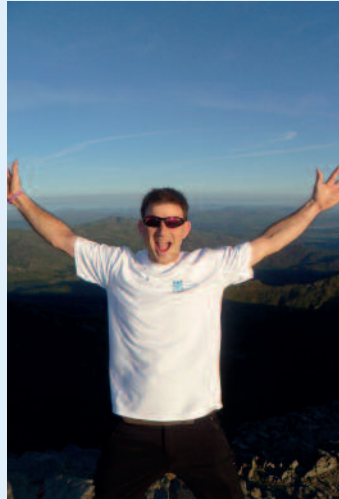
Alnylam also hopes to start testing ALN-AS1 in volunteers in 2015. For more information on Alnylam and how ALN-AS1 tests are progressing, see www.alnylam.com.



WITH THANKS

THREE PEAKS CHALLENGE

Brendan Parfitt and three of his friends completed the *Three Peaks Challenge* in 23 hours and 8 minutes, raising a fantastic £630.00 (this included a donation of £250.00 from Kerry Foods). Laura Parfitt and the rest of the family also sold BPA merchandise to raise funds, Laura is continuing this work and her harmony group has nominated the BPA as one of their charities to receive funds this year. A huge **thank you** to the whole Parfitt family for all of their continued efforts!

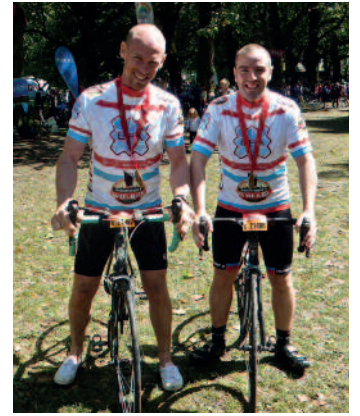


ORPHAN EUROPE

We would like to say an overdue and enduring **thank you** to *Orphan Europe* and all of their wonderful team!

Thank you for the continual support and sponsorship that you have provided for so many of our events not only this year but also over the years – this is in addition to the generous donation last year.

A heartfelt **thank you!**



RIDE LONDON – 2014

We would like to **thank** Ian Burrell and Dougal Betts for completing the *RideLondon100* cycle ride on 10 August for the BPA. As a result of torrential rain and for safety reasons, the organisers shortened the course slightly to 86 miles. Irrespective of the challenging elements, Ian and Dougal were elated to complete the ride safely in 4 hours and 44 minutes, whilst also raising a massive £1,550 (including a £250 donation from Aviva). Here they are at the finish line – smiling as the sun finally came out!

CONGRATULATIONS MR AND MRS LAKE

Michael and Ruth were married in May 2014. Ruth has porphyria and they decided, as the BPA is so close to their hearts, that

instead of giving wedding favours they would make a donation of £160 to the BPA instead. The BPA are touched by this lovely

gesture and would like to say a heartfelt **thank you**, whilst also wishing the newlyweds health and happiness for their future together.

SKEGNESS WEEKENDER

Ray Lancaster and Jenny Coombs organised a whole team to run the *Revolution Custom Van Show* in September. They raised a superb £795 from their tombola, raffle, entry/gate money, donations from an

ice cream and burger van, as well as from attendees. The BPA also ran a stall which raised around £60. After much positive feedback, Ray and Jenny are planning to do it all again next year, in addition to them having lots of fundraising

ideas to be run throughout the year. A sincere **thank you** to Ray and Jenny for all that you and your team are doing. We are already looking forward to next September when they will do it all again – add it to your diaries folks!

EALING HALF MARATHON IN LONDON



Jallil Ettarfaoui ran the *Ealing Half Marathon* (22km) in London on Sunday 28 September. We are delighted that he chose to raise funds

for the BPA; he has currently raised over £1,220. Here he is at the finish line, with some of his friends – well done and **thank you** again!

NEWSLETTER DESIGN

The BPA would like to extend a huge **thank you** to Daniel Wentzell of *Coterie Creative*. Daniel has designed our

newsletter, free of charge, for a number of years now. The newsletters always look terrific and we are immensely grateful

for the magic he performs in transforming it into such a professional and polished piece, ready for printing!

WOODFORDE'S BREWERY – MR AND MRS BETTS

The BPA were touched to receive a generous donation of £200.00 from Mike and Janet Betts, on behalf of *Woodforde's Brewery* earlier this year. **Thank you** Mike and Janet for personally sponsoring the 10 professional grade sports jerseys for the *RideLondon100* event that their son Dougal cycled in this summer.

Do you have any fundraising sporting events coming up? If so, please let us know and we can arrange to send you one of these lovely jerseys.

WITH THANKS

FUNDRAISING

We are extremely grateful for the numerous fundraising efforts from 2014 – all of which have

raised funds and awareness for the BPA. We would be delighted to help you with any event ideas (from *bake*

sales to ice bucket challenges or even *sporting events*), whilst also providing leaflets, merchandise, sponsor forms

or assistance in setting up a JustGiving page – just get in touch!

SALE OF WRISTBANDS/MERCHANDISE

Claire Creag contacted the BPA in May to see whether she could sell some EPP wristbands to her friends and family. Claire was surprised at how quickly she sold the first

100 and, within two weeks, asked for another 100 to be sent. Claire has raised over £408! We are extremely grateful for all of her efforts in raising funds as well as a significant

amount of awareness of EPP and porphyria in her personal awareness campaign – **thank you** Claire.

The BPA were thrilled that the wristbands sold so quickly and

have packs that we can send out to anyone who would be interested in selling some on behalf of the BPA – please get in touch if you would like some more information.

PATIENT EXPERIENCE: PAIN MANAGEMENT COURSE

My name is Teresa Baker; I am 47 years old and was diagnosed with acute intermittent porphyria in 2010. I recently went on a pain management course at the INPUT Pain Unit at Guy's and St Thomas Hospital.

It was a four-week residential course, where we started each Tuesday morning and stayed until Friday afternoon. We had a weekly timetable which was structured to keep us all in a routine. There were nine of us in the group, all of different ages and suffering from different ailments, but we all had one thing in common – we all generally deal with pain 24/7.

The course consisted of four main modules:

- Physiotherapy
- Psychology
- Occupational therapy
- Doctor's talks

Each day started at 9.00 am, and we covered each of the modules through the day and ended about 4.30pm

Physiotherapy

Physiotherapy entailed looking at what we could do and achieve on that day, such as walking up and down stairs, riding on an exercise bike, dancing (I did pull a muscle doing this!) or stretching exercises. I found that after the four weeks I could do quite a lot of these things more easily than I had done before, but most of all I enjoyed the yoga that we did.

Psychology

Psychology taught us about *mindfulness* and *staying in the moment* using specific exercises such as meditation, talking to the group about our lives and getting things off our chests. I found this worked really well for me – it really opened my mind up.

Occupational therapy

Occupational therapy involved trying to achieve a goal. So each Friday, we would set ourselves goals for the weekend. Mostly



OVERALL, THIS COURSE HAS DONE WONDERS FOR MY SELF-ESTEEM AND CONFIDENCE

I achieved mine, but sometimes I didn't and would get frustrated. However, I soon learned that I don't have to be perfect. Once I started to realise this, I didn't get quite as frustrated.

Doctor's talks

The doctor's talk covered

topics such as what medications we were taking and how they affected us.

Overall, this course has done wonders for my self-esteem and confidence, I am still in touch with other members of the group, either just for a chat or to give each other support.

BPA EVENTS:

In 2014...

Our annual **Open Day** was held in Cardiff on Saturday 7 June 2014. Dr Badminton and Tricia Gardiner (NAPS nurse specialist from Cardiff) developed a great programme for us. The feedback was very positive, the day was well attended and everyone seemed to enjoy the balance between the clinical, alternative therapy, mindfulness and patient experience talks, as well as the virtual tour around the laboratory. We received wonderful suggestions for talks and structure which we will try to use for events in the future.

On Saturday 6 September we held our **Autumn Conference and AGM** in

Salford. The timings for this event were extended in order to incorporate a new structure with longer breaks for more informal discussions. Professor Stewart kindly organised the day and delivered a very well-received clinical presentation and a conclusion to the day in the form of a great Q&A session. Two patient experience talks (on EPP and AIP) were also very well received. Again, we received encouraging feedback which we will build into future events, specifically allowing for longer breaks and informal discussions, as well as a new style of Q&A session where questions will be posed to all of the presenters from the day.

Looking forward to 2015:

In 2015, there will be an **International Patient Day** in Dusseldorf, Germany – this will be on Sunday 13 September and will be followed by the main medical conference. Once we have more details of the meeting, we will forward them to you.

Our first face-to-face committee meeting of the year will be held in South Milford, near Wetherby on 14 March 2015. Our committee meetings are open and anyone is welcome to join us.

We are starting to plan our Open Day for 2015 – it will be held in Leeds this year and we are provisionally looking at dates during the Spring Bank school holiday,

which falls between the 25 and 29 May. If it is feasible, we are hoping to run a main session with talks from medical professionals and patients, while also holding a Young People's Workshop, where there will be activities and a less formal structure. For both sessions, we plan to have a lot of breaks for informal discussion, as we are aware of how much people get from just meeting other patients with similar experiences. Once the meeting is confirmed, we will let you know the details.

Please let us know if you would be interested in attending any of these events and we will send you information once it is available.

NEW JOB ROLE FOR THE BPA

The British Porphyria Association are planning to employ a part-time administrator. We are looking for someone who will work on a contract (self-employed) basis, for an average of six hours a week.

The successful applicant will either have knowledge of the porphyrias, or be willing and able to rapidly learn about them. The applicant will need to be self-driven, with a personable and supportive demeanour while also having excellent organisational and administrative skills. They will also need to be a confident computer user with excellent knowledge of Windows-based applications (specifically: Outlook, Word, Excel and Access).

The new BPA administrator will be responsible for a variety of tasks, including: helping to answer member queries on porphyria (mainly email); monitoring and contributing to Facebook; attending meetings on the BPA's behalf; sourcing sponsorship and merchandise; as well as other administrative duties to push the charity forward.

If you are interested in applying for the post, please contact the BPA on helpline@porphyria.org.uk (with "job" in the subject heading) or 0300 30 200 30 for a Job Description and Person Specification. The deadline for applications is 31 December 2014.

FUNDING FOR TRAVEL TO MEETINGS

We love meeting our members at Open Days and Conferences, but we would be delighted to see even more of you attending. Many patients and relatives have reported to us that they benefit tremendously by speaking to others who are having or have had similar experiences. Just that knowledge that you are not alone and that someone understands what you are going through has an immensely positive impact on people.

But we are also aware that, even though we try to move our

meetings around the country, they are sometimes costly to get to. We don't want cost to stop anyone attending, so we are delighted to announce that we have funds available to support our members to attend meetings. If you would like to obtain funding to come to one of our events, please get in touch on 0300 30 200 30 or helpline@porphyria.org.uk. Funding available is up to £50 for travel and £50 for hotels. Funding is not means tested (but receipts will be required).



HOME PHOTOTHERAPY RESEARCH FOR EPP

At our Open Day in Cardiff in June this year, Prof Alex Anstey spoke about a new initiative for people with EPP. Prof Anstey and his team of dermatologists have developed a system for home phototherapy and have managed to obtain a few home phototherapy units to start the research project.

Phototherapy involves exposure to artificial ultraviolet light, usually for a few times a week for a few weeks in the spring, to allow the skin to thicken slightly and develop a tan. This acts as a natural sunblock and may improve tolerance to sunlight. In practice, this can be very

difficult as hospital units are not always accessible and often have limited opening hours. So home phototherapy treatment could help.

Prof Anstey asked if the

PROF ANSTEY AND HIS TEAM OF DERMATOLOGISTS HAVE DEVELOPED A SYSTEM FOR HOME PHOTOTHERAPY AND HAVE MANAGED TO OBTAIN A FEW HOME PHOTOTHERAPY UNITS TO START THE RESEARCH PROJECT.

BPA could help with the purchase of some portable light therapy units. These units cost approximately £2,500 each. The BPA committee have agreed to donate one light unit immediately (out of general funds) and we have opened a new bank account specifically

for fundraising for more. We hope to be able to donate at least one unit per year over the next three years. One of our members started this off by raising an amazing £580

by having his legs and chest waxed, so we are part way to being able to donate two already. **Thank you** Chris Baker for setting the ball rolling in such a painful manner!

Please get involved to help raise funds for this amazing new project.

To ensure any sponsorship funds or donations are allocated correctly, please refer to Light Boxes when sending in funds either by cheque, bank transfer or through JustGiving, or pay direct into the Light Boxes bank account and follow it up with your details in an email to helpline@porphyria.org.uk to enable us to keep our records up to date. Bank details – sort code: 20-43-63, account no: 13526453.

You can also now text Light Box funds to the BPA. To make a payment by text, send the code LTBX14, and the amount you wish to donate, to 70070, e.g. Text LTBX14 £1 to 70070.

NAPS UPDATE

As most of our members will be aware, the National Acute Porphyria Service (NAPS) has recently been changed.

Despite significant efforts from the BPA committee, the porphyria centre at Addenbrooke's Hospital, Cambridge, has now closed. When it became clear that Cambridge was closing, we pressurised NHS England (who manage the NAPS service) to keep Dr Penny Stein. At the last minute, this was successful, and Dr Stein has moved (on a temporary basis) to King's College Hospital, London. She is currently running outreach clinics in Peterborough and

Middlesbrough, and continuing to run an outreach clinic in Leeds with Dr Barth. The other centres all remain as before.

NHS England are asking all NAPS patients (via the NAPS centres) what they have liked/disliked about the service and what they would like to see from the service in future. After considering these replies, NHS England will suggest a number of options for the future. Patients will be asked to choose which of these they think will work best. Only then will a permanent solution be confirmed. We are pleased to say that despite having problems in getting Addenbrooke's Hospital to

listen to us, the BPA have excellent communications with NHS England and we are working closely with them to ensure that the future service will work well for all patients.

The BPA urge you to provide feedback as this is the only way that NHS England will understand your needs as a patient.

Non-NAPS Addenbrooke's patients

If you are a porphyria patient who is not currently covered by NAPS then you have two options:

- If you wish to still attend Cambridge, even though the porphyria centre has now closed, you can be seen in

the metabolic clinic run by Dr Deegan.

- If you do not feel this would be appropriate or if you would like to continue your care with Dr Stein, you can choose to be referred to King's College Hospital. Patients need to ask their GP for a referral to:
**Dr Penny Stein,
Department of
Haematological Medicine,
King's College Hospital NHS
Foundation Trust,
Denmark Hill,
SE5 5RS**

If you have any queries, please do not hesitate to contact us.

LOVE CYCLING? WE NEED YOU!

The BPA have two charity places available for the monumental, televised *Ride London-Surrey 100* sports event on Sunday 2 August 2015. If you are a keen cyclist

and could raise around £500, please consider applying for one of these places. Applicants need to be able to ride 100 miles in less than 9 hours whilst also being

confident in riding in a group. **Contact us to apply for a place in the 2015 event.**

If you would like to apply, please let us know ASAP, as these places will go on a first

come, first served basis – we hope to fill the places by the end of year to allow the successful candidates ample time to train and prepare for the ride.

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.porphyrria.org.uk
email: helpline@porphyrria.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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INFORMAL MEETING NEAR OXFORD AND AYLESBURY

Sam and I have found that one of the best parts of attending BPA meetings is getting the chance to meet other people with porphyria. We have EPP and over the last 18 months, Sam has met with boys of all ages and has had the opportunity to share his experience of similar problems and challenges. To be honest, other children and teenagers quite often disappear if the talks are a bit technical. They find places to sit and play games on their phones where they can turn the lights off. It's an unvoiced understanding – dark is good – let's check out the lights before we settle down and play. For me, the sensible adult (ha ha), chatting to other parents about the daily struggles, things we have found helpful and so on, has been incredibly helpful. In response to how this has helped me, I would very much like to organise an informal get

together for people with acute and cutaneous porphyrias living in an area relatively close to me. I live between Oxford and Aylesbury and would organise a meet-up close to my home.

I work full time, so the gathering would need to be on a weekend and, as I am planning for it to be an informal gathering with no agenda, I would suggest it lasting about 3 hours (with plenty of cake and hot beverages). I anticipate this would appeal to people within an hour's radius of where I live. If you would be interested in meeting up in the spring, please could you contact helpline@porphyrria.org.uk or 0300 30 200 30, with your messages which will be passed to me. If there is sufficient interest, I will organise our get together with great gusto.

Claire Taylor

One of the best parts of attending BPA meetings is getting the chance to meet other people with porphyria.

THE BRITISH PORPHYRIA ASSOCIATION Registered Charity No. 1089609

MEMBERSHIP / DONATION FORM & STANDING ORDER



Title Name
Address

Postcode
Email
Telephone
Type of Porphyria
Date

WAYS TO PAY

- I would like to pay my annual membership fee of £15
 I would like to make a donation of:
 £10 £15 £20 £25 £50 other £
 I would like to set up a standing order (please fill in the form opposite)
 I have set up a standing order using my internet banking*
 I enclose a cheque made payable to the 'British Porphyria Association' for £
 I have made a payment using www.justgiving.com
 I would like a receipt

*please use your name and postcode as reference for an online payment

By making a donation to the British Porphyria Association you will know that you are making a vital contribution to our work. Simply making a small donation will help us raise awareness, man our helplines or support research.

Do you pay UK tax?

If you pay UK tax, the BPA can reclaim 25p of tax on every £1 you give. This does not cost you anything and does not affect your personal tax position. Simply sign and date the Gift Aid declaration.

Standing Order British Porphyria Association

Please send this form to: The Treasurer, British Porphyria Association, Rothlea House, 7-8 Quarry Lane, Butterknowle, Bishop Auckland, County Durham, DL13 5LL
A monthly standing order or any donation you can give will make a difference.

Bank / Building Society name
Branch address
Postcode

Please pay the British Porphyria Association the sum of £
each month / quarter / year (delete as appropriate) from my account until further notice.

Account name(s)

Sort code Account No.

Starting on* (Date)

*This date must be more than one month after today's date

Signed Today's date

This cancels all existing standing orders to the British Porphyria Association
(please tick) yes no not applicable

Please pay to British Porphyria Association bank account:
Sort code: 20-43-63 Account No:7099 6904

Gift aid declaration

I am a UK tax payer and would like the British Porphyria Association (Registered Charity no. 1089609) to treat all donations that I have made in the last six years and all future donations that I make from the date of this declaration as Gift Aid donations, until I notify you otherwise. I understand I must pay an amount of income tax and/or capital gains tax equal to the tax reclaimed on my donations. (I will advise the BPA if my tax status, name or address changes).

Date Signature