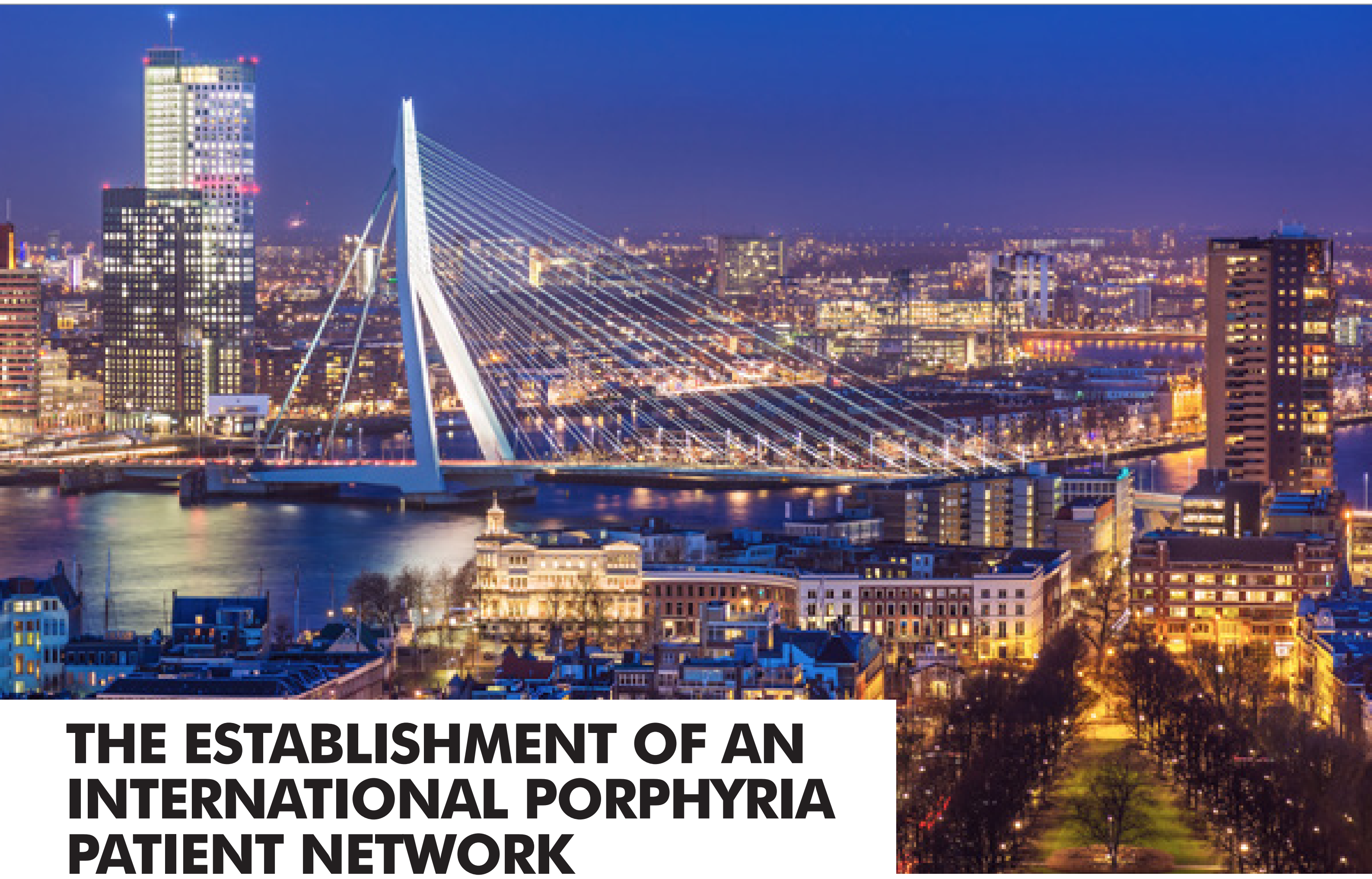
Issue 32 / **June 2016**

THE
BRITISH PORPHYRIA ASSOCIATION
NEWSLETTER

Registered Charity No. 1089609



THE ESTABLISHMENT OF AN INTERNATIONAL PORPHYRIA PATIENT NETWORK

For some time the leaders of patient organisations have felt that it would be useful for the porphyria patient organisations worldwide to be linked in some way. This would give a stronger voice to aspects such as research and access to new medications.

In February this year, an international meeting was held in Rotterdam for porphyria patient organisations. This was kindly organised by the Dutch patient organisation, with the support of a number of other patient organisations from around the world.

John Chamberlayne and Sue Burrell attended from the BPA. There were representatives from the key European patient organisations, along with the Canadian and the American organisations too. The group had a valuable opportunity to discuss what form an international organisation might take. It was agreed to call it the International Porphyria Patient Network (IPPN). The BPA are excited about this initiative and Sue has volunteered to be involved as the UK liaison between the BPA and the rest of the porphyria network.

It was agreed that the IPPN would in no way compete with or aim to replace any of the national patient organisations, such as the BPA. Instead, its ultimate aim is, "To promote, protect and preserve the interests of porphyria sufferers on an international level". Thus, the BPA will continue to work independently to provide our existing service to our members in the UK. The BPA will not financially contribute to the IPPN.

The BPA has already observed advantages to being part of the IPPN. At the NICE meeting for SCENESSE® in March (see separate article), two extra people were able to attend the meeting (two from the BPA and two sent on behalf of the IPPN), which provided a much stronger patient voice. Being united together as part of an international group could provide the BPA with a solid support network in areas such as this.

The IPPN hopes to meet once a year, with other meetings via tele- or video-conferencing. There is much work to be done, from obtaining sponsorship to help with the establishment of an international patient group, through to creating international media campaigns and awareness weeks, etc. As things develop with the IPPN, we will provide additional updates.

THANK YOU AND CONGRATULATIONS

DOYNTON'S HARD HALF-MARATHON

The BPA would like thank **Richard Bennett** for his amazing efforts in running in Doynton's hard half-marathon in February this year – a very dirty affair running cross-country, through rivers and in knee deep mud – where he even lost a shoe at one point! Richard not only finished respectably 220 out of 282 runners, but he was also first in the 70+ age group! **WELL DONE RICHARD** and **THANK YOU** again for raising over £500 for the BPA.

PARACHUTE JUMP

The BPA would like to thank **Laura Parfitt** for her amazing efforts to continue raising funds for the BPA. This April Laura did a parachute jump and managed to raise £400… what an amazing way to raise funds for the BPA. Despite being terrified, Laura looks to have had a great time anyway – **WELL DONE** and **THANK YOU AGAIN** and keep up the great work!

LONDON MARATHON 2016

The BPA were delighted to have two people run in the London Marathon this April – Michael Lake (who managed to obtain his own ballot place) and Alex Gatty who took the BPA's official charity place. The boys were amazing, finishing in 5 hours and 8 minutes and 4 hours and 15 minutes, respectively – brilliant times – you should be very proud of yourselves! The BPA would like to say a massive **WELL DONE** for all of your hard work and commitment to training, as well as a **HUGE THANK YOU** for managing to raise well over £5,400 (including some very generous donations, gift aid donations and an amazing fundraising match of £2,000 from Schroder Investment Management)… and the money is still coming in!

LADIES OF TEIGNMOUTH

The BPA would like to thank Laura Parfitt again for her help in sending through a donation from the Ladies of Teignmouth Tangent Club for £100. This local amateur dramatic society has kindly chosen the BPA as one of their charities to donate funds to, in the hope of helping raise further awareness of the porphyria conditions – THANK YOU VERY MUCH TO ALL INVOLVED.

UPDATE ON SCENESSE®

As members are probably aware, **funding for SCENESSE® in the UK is currently being discussed with NICE** (the National Institute for Health and Care Excellence).

NICE considers whether a drug is likely to benefit patients, whether it will help the NHS meet its targets and whether it is value for money/cost effective. Once NICE issues its guidance, NHS trusts must find the money to make a drug or treatment available. It doesn't give any extra money, or advise how trusts should find the money.

As part of the NICE process, the BPA (along with a number of EPP patients) attended a scoping workshop in March to discuss the proposed evaluation of SCENESSE®. Patient involvement was limited at this stage – further involvement will come at a later stage if the drug is referred for full evaluation. However, we did still have the opportunity to bring up some very salient points regarding EPP.

The meeting started with a brief overview of the NICE process. In summary, after the scoping workshop, NICE, the Department of Health and NHS England will meet to discuss the outcomes of the scoping process and decide whether to take it forward to evaluation. Highly specialised technologies (HST), such as this, then need ministers to formally refer the topic to NICE for evaluation.

In terms of timelines, a referral for this evaluation would be expected sometime between July and September 2016, after which consultees and commentators would be advised of the evaluation period dates. During the evaluation, a few patients would be able to put their personal patient views forward. The BPA will also be able to help by providing data to back up the process, hopefully in the form of surveys which can collect information from larger population numbers.

The process then may pass through another few stages before a final evaluation determination (FED) would be produced. The FED would recommend how the technology should be used in the NHS in England. If there are no appeals, or an appeal is not upheld, the final recommendations would be then issued as NICE guidance, after which point NHS Trusts would be able to provide SCENESSE® via expert centres around England and Wales initially, with Scotland and Ireland hopefully following soon after.

As is evident from the above, the NICE process is lengthy and time-consuming, but we will keep you up-to-date on all developments as they happen.

SCENESSE® ENFANCE – A PAEDIATRIC DEVELOPMENT PLAN FOR CHILDREN WITH EPP

At the Extraordinary Porphyria Patients Meeting in Rotterdam earlier this year, Clinuvel Pharmaceuticals Ltd., not only discussed aspects regarding the rollout of SCENESSE across Europe in adult EPP patients, but they also introduced their plan for the development of a new treatment programme for children with EPP – entitled "SCENESSE® ENFANCE".

As soon as Clinuvel start to dose adult patients with SCENESSE®, at multiple locations across Europe, they will begin developing their paediatric version. They estimate that this will take approximately three years and vast amounts of funds to focus on product development, clinical trials, regulatory filings and the ongoing monitoring and follow-up of patients. However, it is very important to note that the successful completion of the development of a paediatric product is dependent upon wide distribution of SCENESSE® as this will allow for the continued monitoring of the safety of SCENESSE® in the adult EPP population across Europe. The data from this will be captured via the European EPP Disease Registry (EEDR).

As above, the BPA will keep you up-to-date on all developments as they happen. You may also like to visit *www.clinuvel.com* for further information.

ACUTE PORPHYRIAS: NEW SAFE DRUGS LIST – ARE YOU USING THE PINK VERSION?

Drugs that are considered to be **SAFE** for use in the acute porphyrias

This safe list was produced jointly by UK Porphyria Medicines Information Service (UKPMIS) and Cardiff Porphyria Service and is supported by the National Acute Porphyria Service (NAPS). This safe list provides guidance on drugs to use first line, and is not intended to be comprehensive.

N.B. Some drugs may be included under their group name and not their individual drug name.

Abciximab
Acamprosate
ACE Inhibitors
Acetazolamide
Acetylcysteine
Aciclovir
Adenosine
Adrenaline
Alfentanil
Alginates
Allopurinol
Almotriptan
Aluminium salts
Amiloride
Aminoglycosides
Amisulpride
Amitriptyline
Amlodipine
Amphotericin
Angiotensin II inhibitors
Antimuscarinic bronchodilators
Apixaban
Articaine
Aspirin
Atomoxetine
Atovaquone
Atropine
Azathioprine
Azithromycin
Aztreonam
Baclofen
Balsalazide
Barium sulphate
Bendroflumethiazide
Beta-blockers
Bile acid sequestrants
Bisphosphonates
Bumetanide
Bupivacaine
Buprenorphine
Calcium salts
Carbapenems
Carbimazole
Carboprost
Caspofungin
Celecoxib
Cephalosporins
Cetirizine
Chloroquine
Chlorphenamine
Chlorpromazine
Ciclosporin
Cimetidine
Clobazam
Clonazepam
Clonidine
Clozapine
Co-amoxiclav
Codeine phosphate

Cyclopenthiazide
Cycloserine
Dabigatran
Desferrioxamine
Desflurane
Desloratadine
Dextromethorphan
Diamorphine
Diazepam
Dicycloverine
Digoxin
Dihydrocodeine
Dinoprostone
Diphenhydramine
Dipyridamole
Dobutamine
Domperidone
Dopamine
Doxazosin
Doxycycline
Duloxetine
Epinephrine
Eplerenone
Epoetin & analogues
Etanercept
Ethambutol
Etoricoxib
Ezetimibe
Famciclovir
Felodipine
Fentanyl
Fexofenadine
Fibrates[1]
Fibrinolytic drugs
Flucytosine
Flumazenil
Fluphenazine
Fondaparinux
Furosemide
Gabapentin
Ganciclovir
G-CSF
Gemeprost
Glipizide
Glucagon
Glucosamine
Glyceryl trinitrate
Glycopyrronium
Granisetron
Haloperidol
Heparin
Heparins-low molecular weight
Hyoscine salts
Ibuprofen
Immunoglobulins
Indometacin
Insulins
Iodine based contrast media
Iron
Isoflurane

Lacosamide
Lamotrigine
Laxatives
Leflunomide
Lercanidipine
Levetiracetam
Levomepromazine
Levothyroxine sodium
Lidocaine[2]
Linezolid
Lithium
Loperamide
Loratadine
Lorazepam
Lymecycline
Magnesium salts
Mebeverine
Mefloquine
Melatonin
Meloxicam
Memantine
Mepivacaine
Mesalazine
Metformin
Methadone
Methotrexate
Methylphenidate
Metoclopramide
Metronidazole
Midazolam[3]
Mirabegron
Mirtazapine
Mizolastine
Monoclonal antibodies
Morphine
Moxonidine
Muscle relaxants non-depolarising
Mycophenolate salts
Naftidrofuryl
Naloxone
Naproxen
Neostigmine
Nicotine replacement therapy
Nifedipine
Nimodipine
Nitrous oxide
Noradrenaline/Norephinephrine
Nortriptyline
Nystatin
Octreotide
Olanzapine
Ondansetron
Orlistat
Oseltamivir
Oxycodone
Oxytocin
Paracetamol
Paraldehyde
Penicillamine
Penicillins[4]
Pethidine

Phosphate salts
Pramipexole
Pregabalin
Prilocaine
Primaquine
Prochlorperazine
Proguanil
Promethazine
Propofol[3]
Propylthiouracil
Proton Pump Inhibitors
Pseudoephedrine
Pyrazinamide
Pyridostigmine
Quinine
Quinolones[5]
Ranitidine
Remifentanil
Retigabine
Rivaroxaban
Rivastigmine
Selective beta$_2$ agonists
Sevelamer
Sildenafil
Sodium bicarbonate
Sodium fusidate
Solifenacin
SSRIs
Statins
Strontium
Sulpiride
Suxamethonium
Tacrolimus
Tadalafil
Teicoplanin
Temazepam
Terazosin
Terbinafine
Tetracosactide
Theophylline
Tirofiban
Tolterodine
Tramadol
Tranexamic acid
Trazodone
Trifluoperazine
Ursodeoxycholic acid
Vaccines[6]
Valaciclovir
Valganciclovir
Vancomycin
Venlafaxine
Vigabatrin
Vitamins
Warfarin
Zanamivir
Zinc preparations
Zonisamide
Zopiclone

Written May 2016
Review May 2017

Anaesthesia & peri-operative drugs
Articaine
Atropine
Bupivacaine
Desflurane
Isoflurane
Lidocaine[2]
Mepivacaine
Midazolam[3]
Muscle relaxants non-depolarising
Neostigmine
Nitrous oxide
Prilocaine
Propofol[3]
Remifentanil
Suxamethonium

Vigabatrin
Zonisamide

Antidepressants
Amitriptyline
Duloxetine
Mirtazapine
Nortriptyline
SSRIs
Trazodone
Venlafaxine

Anti-emetics
Cyclizine

Dobutamine
Dopamine
Doxazosin
Epinephrine
Eplerenone
Felodipine
Furosemide
Glyceryl trinitrate
Isosorbide mononitrate
Lercanidipine
Moxonidine
Naftidrofuryl

orephinephrine

drugs

Barium sulphate
Bisphosphonates
Calcium salts
Carbimazole
Clonidine
Colchicine
Desferrioxamine
Dextromethorphan
Diazepam
Epoetin and analogues
Etanercept
Fibrinolytic drugs
Flumazenil
Fondaparinux
G-CSF
Glipizide
Glucagon
Glucosamine
Glycopyrronium
Heparin
Heparins-low molecular weight
Hyoscine salts
Immunoglobulins
Insulins
Iodine based contrast media
Iron
Leflunomide
Levomepromazine
Levothyroxine sodium
Lithium
Lorazepam
Magnesium salts
Melatonin
Memantine
Metformin
Methylphenidate
Mirabegron
Naloxone
Nicotine replacement therapy
Octreotide
Orlistat
Penicillamine
Phenylephrine
Phosphate salts
Pramipexole
Primaquine
Propylthiouracil
Pseudoephedrine
Pyridostigmine
Quinine
Rivastigmine
Selective beta$_2$ agonists
Sevelamer
Sildenafil
Sodium bicarbonate
Solifenacin
Strontium
adalafil
emazepam
tracosactide
eophylline
terodine
nexamic acid
deoxycholic acid
ines[6]
nins
rin
reparations
one

arantee that it will be safe
r other complex treatment
to accept enquiries via e-
on 02920 747747.

For those with an acute porphyria…

The SAFE drugs list is produced by the UK Porphyria Medicines Information Service (UKPMIS) based within the Welsh Medicines Information Centre (WMIC) – this is a vital support for those with an acute porphyria.

Each year UKPMIS updates the SAFE list using information collated internationally (via NAPOS – the Norwegian Drug Database for Acute Porphyrias) on drug safety over the previous year. This means that new drugs are sometimes added and at other times, drugs are removed following reports of adverse events.

It is therefore extremely important that acute patients keep an up-to-date copy with them. Please contact UKPMIS on 02920 743877 / 020920 742251 to be added to their database to receive your new copy each year.

There is also a link to the latest database on our BPA website.

The current 2016 version is pale pink. Keep looking out for our bubble each year to remind you which version you should be using!

UPDATE ON ALNYLAM'S ALN-AS1 RESEARCH - AN INVESTIGATIONAL TREATMENT FOR ACUTE HEPATIC PORPHYRIAS

In September 2015, the initial positive data from Parts A and B (Phase 1) of the ALN-AS1 study were reported (relating to asymptomatic "high excreter" patients). Since then, Alnylam has initiated Part C of its ongoing Phase 1 clinical trial. Part C is being conducted in acute intermittent porphyria (AIP) patients experiencing multiple recurrent porphyria attacks, and will evaluate the safety and tolerability of multiple doses of ALN-AS1, as well as measures of clinical activity. This includes changes in attacks (frequency and severity), hospitalisations, use of medications, and quality of life. Alnylam hope to report initial data from Part C in late 2016 – once available, we will provide details in our next newsletter.

Alnylam has also completed enrolment in their EXPLORE trial with a total of 112 patients. EXPLORE is a multinational observational study of AIP, variegate porphyria and hereditary coproporphyria patients with recurrent attacks. The study is providing important information on disease symptoms, attack frequency, current treatment approaches, and the impact of disease on patients and their families. This data will help in the design of future clinical trials of ALN-AS1 or other investigational treatments.

For more information about ALN-AS1, please visit Alnylam's website: *http://www.alnylam.com/patients/alnylam-clinical-trials/.*

LIVING WITH EPP – WINDOW FILMS HAVE MADE A SMALL BUT SIGNIFICANT CHANGE TO OUR QUALITY OF LIFE

In common with many people, I think, who are the only members of their family with EPP and probably diagnosed rather late in life, my approach to managing light sensitivity has been to protect myself from the environment. So, I have spent my life covered up or under cover. It was only when Sam, my son, became light sensitive at the age of eight that I began to think about making the environment a better place for him (and of course for me too). With two people out of a family of three light sensitive it seemed to make sense to make life as comfortable as possible. And, of course, being a Mum, I was (and still am) on a mission to make Sam's life as pain and stress free as possible. Researching options via the BPA and other websites for light sensitive conditions led me to light proofing film. We now use film on our home, car and to some extent at Sam's school too. I know that there are people with EPP using film, especially on cars, with great success so I am not presenting anything new, but I also know, from contact through meetings and social media that there are people with EPP who haven't explored this option; as a result, I wanted to explain how useful we have found film for improving our quality of life.

Although amber film gives the best coverage, we have chosen to have clear film on the south facing windows of our house – it has certainly given a level of protection which stops me panicking to shut the curtains if I see Sam sitting near a window. At school, the site manager called me with a problem: in one of the tech rooms, all the tools were fixed alongside a large window. Curtains and blinds could not be used due to safety issues and the tools are static so Sam had to access them in-situ. I suggested using clear film and it was greeted with enthusiasm as a simple 'fix'. The school already had a company providing film for various uses (tinting windows, reflective effects and so forth) and so it proved to be a simple job for the company to obtain the film I specified and fit it. Since then our lovely site manager has used it on a number of occasions where other window covering is problematic. Having asked around, it seems that film is used on public buildings, including schools, a great deal and most county councils have firms providing this, so it is just a matter of giving them the film specification required.

The most important film we use is on our car. Initially, I had clear film fitted to all the windows and this was very effective. I cannot describe the joy of driving without long sleeves, gloves and scarf over my face and the knowledge that Sam didn't need to keep swapping around in the back to avoid the sun. After seven years the film deteriorated. Unfortunately our car is parked on a south facing drive which accelerated this process. As Sam's skin had become so problematic we had film re fitted last year with clear film on the windscreen and front windows and amber on all the rest. The amber film ensures complete comfort and safety for Sam. When I think of the stress of journeys prior to having the film fitted compared to driving in our lovely, safe, light proof box, I just wish I had had film fitted much sooner. My light proof car has improved my quality of life more than anything else over 52 years of light sensitivity.

By Claire

EVENTS IN 2016:

BPA PATIENT MEETINGS/EVENTS 2016

Our **Open Day** will be held on **Friday 8th July 2016** (10am to 4pm) at Salford Royal Hospital. We will have some updates on developments with regards to access to SCENESSE (a potential treatment for EPP) and the Alnylam research (a potential treatment for the acutes), as well as presentations from doctors and patient experience talks from EPP and AIP patients. We are also excited to be trialling a slightly different structure for the meeting. In addition to these structured talks, we also plan to have some 'table' style discussion groups to focus on different aspects, such as issues affecting children and teenagers, the various transition stages for the different porphyrias, as well as tables for patients and those providing support to patients, to name a few!

Our Autumn Conference and AGM will be held at the **Holiday Inn Peterborough West** on **Saturday 1st October 2016** (10am to 4pm), with the support of Dr Stein and the team from Kings College Hospital London. Again, we will have updates on Clinuvel and Alnylam as well as various other talks from doctors, nurses and patients about living with porphyria. There will be plenty of opportunities to talk with others affected by porphyria, as we plan to group sessions together to allow a specific cutaneous section and an acute section, meaning that people will be able to use a breakout room for informal discussions, instead of attending talks that may not be as relevant to them.

Please let us know if you would be interested in attending either event as, based on the popularity of our 2015 events, we expect places to fill quickly. Please forward the names of anyone wishing to attend with you to: *sue.burrell@porphyria.org.uk* or call 0300 30 200 30 to confirm your attendance. The BPA will send further information to those interested a few weeks before the actual event.

SAVE THE DATE

Every two years, an International Patient Day is held in conjunction with the Porphyrins and Porphyrias Congress, which brings together porphyria experts and researchers from around the World. The Patient Day, in turn, brings together patients and patient organisations from around the world. We are able to announce that the next International Patient Day is now scheduled. It will be held in the beautiful city of Bordeaux on the west coast of France, on Sunday, 25th June 2017. Further details will follow as soon as we have them.

FUNDRAISING PLACES 2016:

WE NEED SPORTING FUNDRAISERS FOR 2016

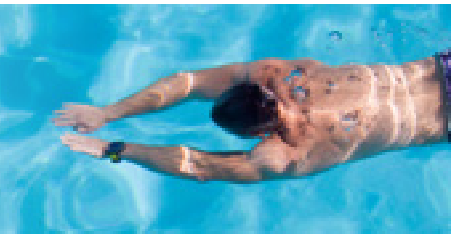
The BPA have a number of places in some very popular sporting events in 2016. Please let any of your friends or family know about these, if you think they may be interested. We can send you specific details to forward on, if desired. Please contact *sue.burrell@porphyria.org.uk* for more details or to express your interest in applying for one of these charity places.

LOVE RUNNING?

The BPA has five places in the Great South Run on Sunday 23rd October 2016 – this event is a half marathon (13.1 miles) from Southsea to Portsmouth.

LOVE SWIMMING?

The BPA have four places in the Swim Serpentine on Saturday 24th September 2016 – this event is a 1-mile open water swim in Hyde Park, London.



These places will go on a first come, first served basis, so please contact the BPA, via: sue.burrell@porphyria.org.uk or on 0300 30 200 30, ASAP to confirm your place.

GOOD LUCK

The BPA would like to wish all of our fundraisers the best of luck in their training and fundraising for the different events that are scheduled over the coming months, from: the Great North Run, the Great South Run, Swim Serpentine and Ride London-Surrey 100, to name a few. If the BPA can help provide you with our branded running/cycle tops, fundraising packs, sponsorship forms, or anything else, please just get in touch: *helpline@porphyria.org.uk or 0300 30 200 30.*

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
Vice-chairman: Liz Gill
Treasurer: Anne Newton
Secretary: Jacqueline Binns
Administrator: Sue Burrell
Patrons: Prof. George Elder, Dr. Mike Badminton, Prof. Felicity Stewart Prof. Timothy Cox

NAPS SCOTLAND

The BPA are delighted to report that NHS Scotland has finalised arrangements to commission support for Scottish acute porphyria patients and their doctors from the English NAPS service. The new arrangements came into operation as of 1 April 2016.

A formal agreement has been made to enable shared care between NAPS doctors (mainly Dr Mike Badminton from Cardiff) and either Dr Alison Cousins or Dr Peter Galloway from Scotland. Outreach clinics will be held once every six months in either Edinburgh or Glasgow. This means that patients in Scotland suffering attacks of an acute porphyria will benefit from the knowledge and best practices of NAPS, while still being seen through an effective network with local porphyria specialists. Doctors caring for hospitalised patients will be able to access the NAPS out-of-hours clinical advice service, which will ensure appropriate access to haem arginate treatment for patients in Scotland.

The aim is that new patients will be seen within six weeks initially, although this may take the form of a virtual appointment or telephone consultation to establish what support is needed. Patients will then be offered an appointment for one of the scheduled outreach clinics.

NAPS contact details: this is the emergency number at the University Hospital of Wales: *029 2074 7747.* This 24/7 number should be used at all times for new patients, and out of working hours for existing NAPS patients.

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