



UKPIPS Community Newsletter

Issue 2 – July 2023

Welcome:

Welcome to Issue 2 of our Community Newsletter. We hope you find it interesting, and we would be very keen to receive any thoughts you have and any topics you would like us to include. We look forward to hearing from you, you can contact us via the website or via the email address below.

Trustees:

We are very sorry to say that Paul Harris has had to step down as a Trustee due to ill health. We are grateful to Paul for the contribution he made, both in working on strategic plans and the Community Event held in February. We wish him well for the future.

Sue Dimmock offered to be co-opted as a Trustee and Margaret Fuller was very pleased to accept as Sue has been working hard for UKPIPS both with her support of the community on Facebook and also representing UKPIPS on NHS England Committees and Patient Groups.

We advertised for new Trustees and are very pleased to announce that David Cohen and Gary Narborough have been co-opted to the Board of Trustees until the AGM in August. At the AGM in August Margaret Fuller will be stepping down as a Trustee having completed her second 3 year term.

A brief synopsis introducing Gary Narborough:

I have recently been co-opted as a Trustee because I'm really passionate about patients with primary and secondary Immune Deficiency disease. So, this is about our treatment and our welfare in and out of clinical settings.

I am originally from New Zealand and was born with Hyper IGM Syndrome. I have resided in the UK for quite a while now holding dual nationality. I'm quite aware of the journey we go through from diagnosis to final treatment, which in my case was 37 years. I was originally diagnosed when Immunology didn't exist and my childhood was really difficult. I am now a pensioner, turning 69 very soon.

A brief synopsis introducing David Cohen:

Hello, my name is David Cohen and I am pleased to be recently elected to the Board of Trustees for UKPIPS.

I am based in the North West of England, and have been associated with the community of Primary Immunodeficiency patients for twenty years, as both my wife and son have PID conditions. I am very familiar with the rollercoaster of emotions and understanding that affect patients and clinicians with these challenging conditions.

UKPIPS Registered Charity 1148789

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My work brings me regularly into the sectors of the National Health Service and Central Government, so I am familiar with the limitations and difficulties that can arise on both sides of the divide in providing effective support to patients and their carers. I hope to be able to bring these insights as I learn the ropes as a Trustee and help UKPIPS continue the vital work of promoting PID patient needs and improving services for the PID Community. I look forward to working for you and meeting you (either virtually or in person) in the future.

NHS News:

Covid Medicines

As I'm sure you are aware, processes for accessing Covid medicines in England changed at the end of June, when commissioning of treatments moved to Integrated Care Boards (ICBs) away from NHSE. Hopefully you will have received a letter from DHSC about this?

It's important to note that posting a positive test result on the government website no longer generates an automatic call-back, and the onus is now on you (or your carer) to access treatment.

The latest DHSC / NHSE advice is to call your GP, 111 or your hospital team. This is fine for working hours but out of hours access much less clear. UKPIPS and other charities have written to Steve Barclay about this and await a response.

Some ICBs do have processes in place that follow the old CMDU (Covid Medicines Delivery Units) access whilst others are relying on GPs as the access point. As things are unclear, my advice would be to check your local ICB website to see if you can find any relevant information. If not, you still have the fallback position of GP, 111 and hospital teams.

UKPIPS has been contacted by one ICB (covering Barnet, Camden, Enfield, Haringey and Islington) with information, which I have included below.

However, there is no requirement for ICBs to inform patient groups, so could I please ask that if you do receive formal notification of local processes, you either post them up on our closed Facebook group or email sue.dimmock@ukpips.org.uk with details. This way we can share as much information as possible.

Access to Covid Medicines for the London boroughs of Barnet, Camden, Enfield, Haringey and Islington

Under the new arrangements, patients in Barnet, Camden, Enfield, Haringey and Islington, eligible for Covid medicines, who test positive for COVID-19, will need to self-refer to the new North Central London (NCL) COVID Medicines Service to be assessed for treatment.



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Patients can access this general-practice led service either via their own GP practice, via NHS 111 or by contacting the NCL COVID Medicines Service directly:

- Telephone: 020 3838 7121 (available 10am to 1.30pm Monday to Friday and 10am to 12noon Saturday and Sunday).
- Email at nclcb.cmdu@nhs.net (Mailbox is monitored 9am to 5pm Monday to Friday and 9am to 2pm Saturday and Sunday).

More details are published on the website: <https://nclhealthandcare.org.uk/.../covid-19-treatments/>

UK Plasma Fractionator

We hoped by now to have received notification of the newly appointed fractionator for UK plasma, but things have been moving slowly and rightly so as this is a hugely significant move for NHSE after 20 years of the plasma ban. One piece of good news is that immunoglobulin is no longer the only approved product for production from plasma. From 3rd July 2023, albumin was also approved by the MHRA, making the fractionation of UK plasma a much more viable and cost-effective process for manufacturers. Albumin products are given to thousands of critically ill patients each year after blood loss from injuries or severe burns, as well as certain medical conditions.

Fundraising:

UKPIPS' sincerest thanks go to Jodie Lath and her partner Joe who, for the second year running, held a pinball fundraiser in aid of UKPIPS at their pub the White Horse Inn in Swavesey, Cambridge, between 30th June and 2nd July. This raised the incredible sum of £1,792.14 which allows us to continue supporting all of our community.

THANK-YOU Jodie, Joe and baby Arlo!!

Volunteering for UKPIPS:

Once again, we are in a position of needing your support to keep the charity operational. Despite fantastic efforts by people like Jodie, and small project-based support from one of two of the large pharmaceuticals, UKPIPS relies on volunteers to keep it running. We have just one paid member of staff (Carolyn) who works just 10 hours a week - everything else is done by our volunteers, including all of the fantastic help we get with our Social Media



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platforms; our IT and our Accounting functions as well as our Trustees and those who maintain contact with the NHS, medical panel and pharmaceuticals.

We currently would love to hear from anyone who is interested in giving something back (be it you, a family member or friend) who has skills in the areas of Fundraising, Marketing or Social Media platforms. Please get in touch and one of our volunteers will arrange to call you for a chat (admin@ukpips.org.uk).

Other News:

- The recording of our Community Event held in February can now be viewed following the links from our Website.
- We have just received confirmation that we have secured our PIF TICK Accreditation for another year. This means that our literature is produced using a PIF TICK accredited procedure and readers can be assured that what they are reading is current and up to date with medical references (where appropriate) checked by members of our Medical Panel. If you would like to be part of our User Panel which looks at our literature from a user's perspective, please get in touch via the email below. If you have any questions regarding our PIF TICK Accreditation, please email below.
- We are grateful to members of the Community who have agreed to make a monthly donation to UKPIPS. This helps us to run the charity and to keep in touch with you. If you would like to donate to UKPIPS, visit our donations page for more information <https://ukpips.org.uk/donate/>

Keep in Touch:

You can contact us at info@ukpips.org.uk, find us on Facebook and LinkedIn or visit our website www.ukpips.org.uk. Do tell us what you would like to read in future issues of our Newsletter.