



UKPIPS Community Newsletter

Issue 2 November 2024

Welcome from your Trustees

We held our AGM on 3rd August and a new Trustee team was voted in:

- Sue Dimmock (Chair)
- David Cohen (Deputy Chair)
- Judith Gower (Trustee)
- Andrew Morris (Trustee)
- Gary Narborough (Trustee)

Judith and Andrew are new to the Trustees team and both have an immune-deficiency. You will see their personal introductions further into this newsletter. Having such a strong team, with a diverse range of interests, means we are in a robust position for the first time in a while. We are working on meeting all the requirements of the Charities Commission in terms of new policies and have just completed our latest Business Plan.

If you have any areas you feel we should be focussing on, please do not hesitate to get in touch as this Charity continues to be run by volunteers who understand you and your condition. Equally, if you are interested in joining our volunteer management team, we'd love to hear from you. You can contact us by email: Trustees@ukpips.org.uk

New Trustee Introductions

Hello everyone, my name is Andrew Morris I would like to thank you for affording me the opportunity to serve on the Board of Trustees for UKPIPS. Like many of us within the community I too have a Primary Immunodeficiency amongst other conditions and like many of you I have found it tough at times coming to terms with the nature of the condition. Why did I wish to serve as a trustee on UKPIPS? The answer to this is quite simply. I wanted to help support an organisation that provides support to our community and that can help influence the medical community in being able to understand more about the patient's journey. On a more personal level I have three daughters, two of which have the same condition as myself.

I hope to make a positive contribution in the development of UKPIPS and give something back to the community following my appointment.



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My name is Judith Gower and I have recently been elected to the Board of Trustees for UKPIPS.

I am based in Hertfordshire and have been associated with UKPIPS ever since I was diagnosed in 2012. I attend Addenbrookes and have met some of you there at Patient days. I worked as a solicitor for local government until I finally retired in 2023. I have experience of charity, company and data protection law all of which I trust will be useful as a Trustee. Like many of you my PID has caused many other problems. I also understand the problems of trying to get past GP receptionists who can't believe that we are expert patients. I look forward to working on your behalf to provide effective support to patients and carers as well as promoting the needs of PID patients and services for all of us.

NHS News

NHS UK Plasma Update

It is with great pleasure that I can now share the news that Octapharma have been appointed as the Fractionator for UK plasma following a couple of years' hard work on the tender exercise.

The detail below was recently released by the Medicines Procurement and Supply Chain (MPSC) at NHSE.

Background

In 2021, the Medicines and Healthcare products Regulatory Agency (MHRA) and the Commission on Human Medicines (CHM) approved the removal of the ban on UK-sourced blood plasma for the manufacture of immunoglobulins. Following this decision, the government appointed NHS England to develop and lead a procurement to select a supplier to provide fractionation services for England, as well as to lead on a UK Plasma Programme. In 2023, the MHRA and the CHM also approved UK plasma for use in the manufacturing of albumin. This followed advocacy work by NHS England and NHS Blood and Transplant (NHSBT), in collaboration with other blood services and organisations, for the safety of UK plasma.

UK Plasma Programme

The UK Plasma Programme is being led by England, with the option for the Devolved Administrations for Northern Ireland, Scotland, and Wales to participate.

For the first time in decades, the programme provides the UK with an opportunity to establish domestic plasma for medicines collections that will improve the resilience of our supply chain that remains at risk due to the volatility of the globally sourced supply that we are solely reliant on.



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By improving the supplies of albumin and immunoglobulin to the NHS, the programme will ensure patients in the UK are more likely to retain access to recommended treatments and reduce the need to be treated with an alternative product.

In England, the NHS has infrastructure in place through NHSBT to collect plasma, through whole blood donations and via plasmapheresis at three dedicated plasma donor centres, which will enable England to establish a domestic supply of plasma derived medicinal products (PDMPs) that will meet a proportion of total demand; while continuing to source products manufactured using non-UK plasma.

Over the past two years, NHSBT has been collecting source and recovered plasma, and will continue to collect more than 250,000 litres per year throughout the life of the programme. NHSBT is actively recruiting new donors to build on the donor base. By the end of March 2025, NHSBT will have doubled their donor base, ensuring that they can sustainably collect 10,000-12,000 litres of source plasma a year.

Fractionation procurement

Following evaluation and moderation of procurement bids, NHS England has now completed a procurement process, with the support of the UK government, NHSBT, and the Devolved Administrations.

In July 2023, NHS England appointed a sole fractionator, Octapharma, to proceed into the mobilisation phase of the procurement. Octapharma, established in 1983, are one of the world's largest plasma fractionators. Octapharma have been supplying the NHS with plasma derived products for more than 30 years.

The procurement will focus manufacturing on the highest volume products: low (5%) and high (20%) strength albumin, and 10% intravenous immunoglobulin (IVIg).

The initial contract period is 5 years, which begins from the supply date of the first product, expected no earlier than Q1 2025. There is an option to extend the contract for up to an additional 2 years.

Mobilisation

The mobilisation phase of the project began in August 2023 following contract award, and consists of:

- Plasma Readiness – focussing on the collection, testing, release, export, and shipping plasma collected by NHSBT.
- Regulatory and Licensing – including audits at both NHSBT plasma collection and processing sites, as well as fractionator manufacturing and bottling locations. During this stage, regulatory import and manufacturing and product licenses are granted.
- Operational Readiness – focussing on the receipt of plasma and fractionation, packaging, importation, and distribution of finished goods.



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- Implementation – centring on the clinical engagement to deliver uptake of the products, system readiness for ordering, receipt, and distribution, creation of product allocations and uptake tracking tools, and commencing patient treatments on the new products.

In August 2024, the MHRA completed the regulatory process, granting approval for the UK Plasma Master File and Marketing Authorisations for low (5%) and high (20%) strength albumin and 10% intravenous immunoglobulin (IVIg), to include the use of UK plasma. Substantial progress has been made and NHS England has already started working with clinicians, pharmacists, transfusion, and nursing staff to plan for implementing these new products from Q1 2025.

The Medicines Procurement and Supply Chain (MPSC) team will provide updates on progress against the mobilisation plan to Clinical Reference Groups (CRGs), expert speciality working groups and patient representative groups.

Donating Plasma

There is a growing need for the unique medicines made from plasma. NHSBT works in collaboration with patient groups such as UK Primary Immune-deficiency Patient Support (UKPIPS), Immunodeficiency UK and United Kingdom Plasma Action (UKPA) to promote UK plasma, recruit more donors and educate other stakeholders on why self-sufficiency of UK plasma is essential.

People can donate plasma more often than they can donate blood, because the recovery time is shorter. For more information about Plasma donation or how to donate, visit:

www.nhsbt.nhs.uk/what-we-do/blood-services/plasma-donation/.

If you know someone who is interested in donating plasma but they haven't got a donation centre nearby, they can also help by donating blood. NHSBT can remove plasma from blood donations to freeze and make into medicines.

Winter Vaccination Programme

Across the UK programmes for Flu, Covid and RSV (Respiratory Syncytial Virus) are now in operation.

England:

The main flu and COVID-19 vaccination campaign commenced on Thursday 3 October 2024. The start date for COVID-19 vaccinations aligns to flu to support co-administration of flu and COVID-19, but in some areas they will continue to be delivered separately.

This vaccination schedule is expected to be completed by **Friday 20 December 2024**.

Anyone in England can use this link to the national booking service for flu and / or COVID vaccination:

[Book, change, or cancel a COVID-19 vaccination appointment online - NHS \(www.nhs.uk\)](http://www.nhs.uk)



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RSV – this is the first year the RSV vaccine is offered and it will be available all year round. The RSV vaccine helps protect against respiratory syncytial virus (RSV), a common virus that can make babies and older adults seriously ill. It's recommended during pregnancy and for adults aged 75 to 79, so you should be advised of its availability if you fall into either of these two groups. It's best to check with your GP.

Northern Ireland:

For Northern Ireland, the latest update advises you to contact your GP Surgery to find out about their vaccination programme:

nidirect.gov.uk

The autumn and winter vaccination programme, which includes the COVID-19 booster and f
For RSV, see England.

Scotland:

Flu and COVID-19 vaccines will be offered to those eligible between September and December. If you're eligible, you'll receive a letter, SMS or email with appointment details or information about how to book one. You may receive information about your appointment at a different time than previous years.

Please do not try to make an appointment until you've been invited by NHS Scotland.

The following link provides more details:

<https://www.nhsinform.scot/winter-vaccines/>

For RSV, see England.

Wales:

Eligible individuals (which includes those with immune-deficiency) will receive an appointment invitation from their local health board.

COVID-19 vaccination programme | GOV.WALES

Regards the **flu vaccine**, this can be obtained at your GP surgery or at some community pharmacies. If you work in health or social care, ask your employer where to get your vaccine.

For RSV, see England.

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.

We wish you all the very best for the forthcoming festive season and sincerely hope you stay well throughout.