



April
Newsletter

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Welcome to the April Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the April newsletter. We hope you find the information useful to you.

Read on for our monthly news round up and, don't forget to [visit us on Facebook](#) to get updates throughout the month.

Plasma Reception at Parliament Spotlights Vital
Need for UK Plasma Donors





On March 20th, Immunodeficiency UK played a pivotal role in the Plasma Parliamentary Reception at the House of Commons.

Sponsored by MP Munira Wilson, this momentous event brought together MPs, healthcare professionals, and patients to discuss the critical importance of plasma donation in the UK.

Shining a Light on Life-Saving Plasma

The reception, organised by the NHS Blood Transfusion Service (NHSBT), raised awareness about the life-changing impact of plasma-derived therapies like immunoglobulin for those with immunodeficiencies. As plasma contains vital antibodies, immunoglobulin therapy made from donated plasma is essential for survival and quality of life for many patients.

Immunodeficiency UK: A Vocal Advocate

Our charity actively participated, alongside Societi UK, highlighting the growing need for more UK plasma donors. The number requiring immunoglobulin treatment has risen 31% in 5 years, underlining the urgency of boosting domestic plasma supply.

Our CEO Susan and patient representative Margaret, affected by CVID, shared how immunoglobulin shortages impact health and well-being. Margaret

emphasised: "It's reassuring to know UK-donated plasma will produce our immunoglobulins. It's vital more people donate to keep us well."

Susan told MPs: "Plasma is precious. Over 7,000 UK antibody deficiency patients depend on plasma-derived immunoglobulin. Demand outstrips supply, so collecting UK plasma prevents shortages and ensures continuity of care." Demand outstrips supply, so collecting UK plasma will help prevent shortages to ensure better continuity of care.'

The Road to Better Self-Sufficiency

While the UK previously relied on imported products, plasma donation restarted in 2021 – a major step towards self-sufficiency. The Plasma for Medicines programme aims for a long-term, secure domestic supply.

Immunodeficiency UK would like to thank all our patient representatives who volunteered to speak to parliamentarians about the importance of plasma at the event.

To learn about plasma donation or getting involved, visit the [NHS Blood and Transplant site](#).

Free Public Webinar: COVID-19 & Immune Systems

Wondering how COVID-19 affects those with weakened immune systems?
Curious about the [STRAVINSKY](#) study?

Join the STRAVINSKY team for a FREE public webinar on April 24th at 6:00 PM.

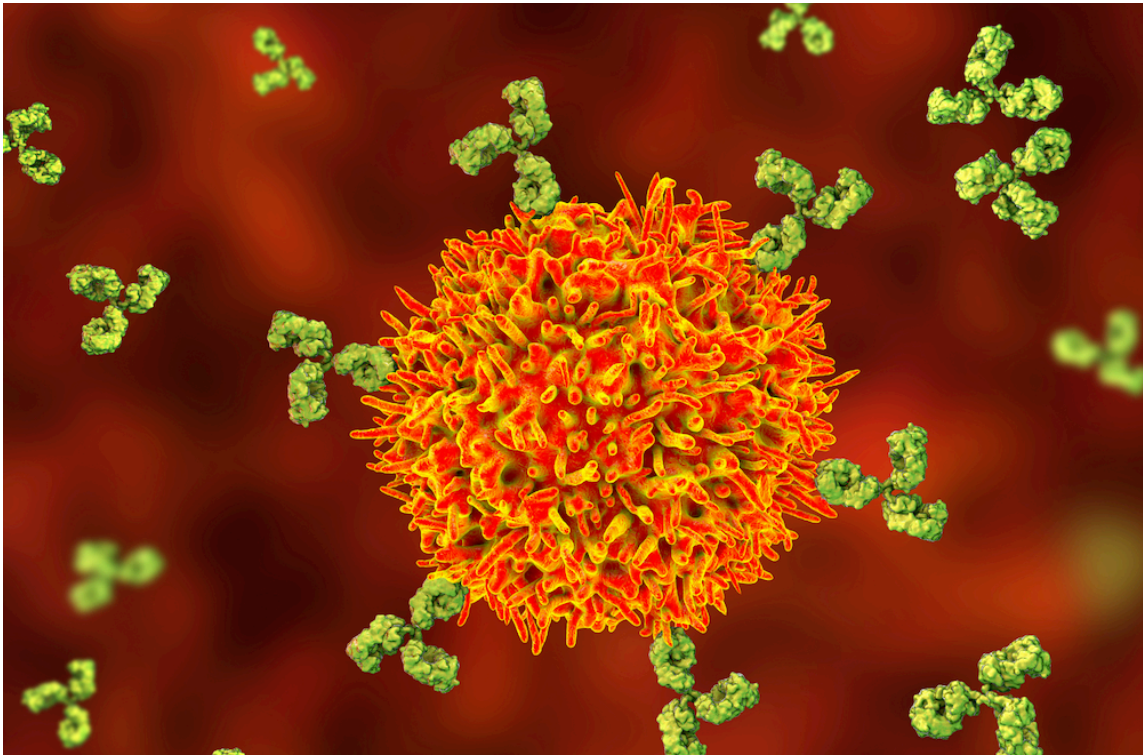
Get the latest updates on:

- STRAVINSKY's ground-breaking research on COVID-19 vulnerability.
- Current COVID-19 guidance for people with weakened immune systems.
- How YOU can participate in the study.

Got questions? Ask the expert speaker, Professor Alex Richter. Submit questions in advance or ask them live!

 [Register for FREE today.](#)

Immunoglobulin supply issues



Immunodeficiency UK understands that Kedrion have taken the decision to reduce the supply of their immunoglobulin product Subgam in the UK by 50 percent. Below is a statement from the company explaining their position.

Supply of Subgam in the UK - statement from Kedrion

‘Throughout our history, we have stood by the National Health Service and Patients Associations in supporting individuals facing challenging health circumstances.

Our dedication to providing high-quality plasma products to those in need has been unwavering, as we recognise the crucial role these products play in improving the lives of patients across the UK.

Unfortunately as a result of the evolving market dynamics within the UK plasma products sector it has been necessary to reduce the volume of Subgam supplied. This has been a difficult but necessary decision to ensure sustainability of our wider portfolio of products.

As a result of this Kedrion is working with the Medicines Procurement and Supply Chain (MPSC), who are working in collaboration with the sub-regional Immunoglobulin Assessment Panels (SRIAPs) to ensure a suitable alternative

treatment is provided where necessary. Your healthcare professional team will inform you if your treatment will need to change or not.

We understand the difficulties that a change in treatment can bring, and the decision to reduce the supply of this treatment was not taken lightly, but is essential in ensuring the sustainability of our product portfolio.

As part of the Kedrion group of companies since the end of 2022, we are dedicated to continuing our partnership with your organisation and all the patients that you support and represent, adapting our product offerings to ensure long-term sustainability and accessibility of blood plasma products for those in need.'

If you have to switch immunoglobulin products take a look at [our leaflet](#) on this topic.

Ongoing Struggles for the Immunocompromised on Lockdown Anniversary



On the 4th anniversary of the first UK COVID-19 lockdown, Immunodeficiency UK joined 15 other charities and patient groups in a joint letter to Prime Minister Rishi Sunak.

The letter highlighted the continued high-risk and isolation faced by immunocompromised individuals across the UK, as we enter the 5th year of the pandemic.

We called on the Prime Minister to ensure regulatory authorities prioritise the assessment and implementation of new preventative treatments, so immunocompromised people no longer have to wait and sacrifice so much.

Immunodeficiency UK remains committed to advocating for the needs of the immunodeficiency community during this difficult time. We will continue working

with partners across the sector to drive the policy changes necessary to support the immunocompromised. Read the letter [here](#).

Resilient Jasper's Life-Changing PID Diagnosis



For Sophie and her son Jasper, the diagnostic odyssey was long and challenging before finally receiving answers last August. At just 8 months old, Jasper began showing concerning symptoms like fatigue, fevers, and appetite loss. Despite countless doctors' visits and antibiotics, nothing helped. "For five years, Jasper showed incredible strength adapting to this mysterious illness," shares Sophie.

"But the hardest part was when we'd take him to the hospital, he often seemed healthy - even dancing around! At times, I felt like I wasn't being believed as a parent."

It was only thanks to the relentless advocacy of Jasper's consultant, Dr. Mazah, that they were finally referred to the immunology team. Under their care, everything changed.

Before treatment, Jasper was hospitalised around six times yearly and on constant antibiotics. Since starting his specialised care, he hasn't been hospitalised once and his antibiotic need has dropped dramatically.

"He sleeps through the night, has an amazing appetite, and loves playing with friends at the park - something we couldn't imagine before!" says Sophie. "Our whole family's life has improved immeasurably."

The diagnosis? Jasper has a rare primary immunodeficiency called APDS, specifically a *PIK3CD* gene mutation, making him the only known child in Wales with this diagnosis.

"Thank you to the immunology team whose dedication has given Jasper a chance at a healthier, happier future," Sophie shares gratefully.

Jasper's incredible resilience and his family's perseverance demonstrate the life-changing impact of an accurate PID diagnosis and proper treatment. His journey reminds us why rallying awareness and support is so vital.

Read Jasper's patient story [here](#).

Dates and useful links for the 2024 COVID-19 Spring booster programme

In England: Boosters will start in care homes on 15 April, and for all other eligible people on 22 April. You can book boosters via the [National Booking System](#). The booster programme will run until 30 June 2024.

In Scotland: The booster programme will run from 1 April until 30 June 2024. [Spring coronavirus \(COVID-19\) vaccine | NHS inform](#)
Helpline: 0800 030 8013

In Wales: The booster programme will run from 1 April until 30 June 2024. [COVID-19 vaccination information - Public Health Wales \(nhs.wales\)](#)
If needed you can contact your [Local Health Board](#).

In Northern Ireland: The booster programme will run from the 15 April 2024. An end date has not been given. [Get a COVID-19 vaccination in Northern Ireland | nidirect](#)
If needed you can contact your [Health and Social Care Trust](#).

If you live in England, Wales and Northern Ireland there is additional help via the relevant NHS helpline: [119](#).

Wear Your Support with the Immunodeficiency UK Pin Badge



Make a statement and raise immunodeficiency awareness with our exclusive Immunodeficiency UK pin badges!

These stylish and eye-catching enamel pins let you flaunt your support in an impactful way. Each high-quality pin features our iconic logo in vibrant colours - the perfect subtle yet meaningful accessory. Adorn your jacket, bag, hat or anything else with this badge to wear your commitment with pride.

The best part? Every purchase directly contributes to our mission of improving lives for those with primary and secondary immunodeficiency through advocacy, education and support services. At just £2 each, these affordable pins make great gifts for yourself or immunodeficiency warriors in your life.

Key Features:

- ✦ Durable enamel pin with bold Immunodeficiency UK logo
- ✦ Vibrant design to customise any outfit
- ✦ Affordable at £2 each + 79p postage
- ✦ Proceeds benefit immunodeficiency advocacy & services

Order your Immunodeficiency UK pin badge today.

Thank You to Our London Landmarks Half Marathon Superstars!



We are so grateful to Katie, Andy, and Jackie for taking part in the London Landmarks Half Marathon and raising over £2,300 (including Gift Aid) for Immunodeficiency UK!

Katie has an immunodeficiency condition, and she completed the race alongside her husband Andy and her sister Jackie to show their support for our important work. The funds they've raised will make a real difference in helping people living with primary and secondary immunodeficiencies.

We're in awe of Katie, Andy, and Jackie's dedication and commitment to this cause that is so close to their hearts. Their achievement is all the more impressive given the training and preparation required to take on a challenge like the London Landmarks Half Marathon.

If you'd like to show your support for Katie, Andy, and Jackie's fundraising efforts, you can still donate to their fundraising page here:

<https://www.justgiving.com/fundraising/Katie-Andy-Jackie>

On behalf of everyone at Immunodeficiency UK, thank you Katie, Andy, and Jackie for using this event to raise vital awareness and funds.

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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