IMMUNO
DEFICIENCY
UK

Welcome to the June Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we introduce you to Valerie, our new chair of Trustees, update you on our advocacy activity and there is a call-out for research participants.

Read on for our monthly news round up and you can get updates throughout the month by visiting us on Facebook.

Grifol has provided a grant for the creation of the newsletter with no input into content.

A fond farewell to Dr Matthew Buckland – and a warm welcome to Valerie

As our charity continues its journey supporting people with primary and secondary immunodeficiency, we want to take a moment to say a big thank you and goodbye to Dr Matthew Buckland, who has stepped down as Chair of Trustees and Chair of our Medical Panel.

Dr Buckland's commitment over the past 12 years has helped shape who we are today – a stronger, more responsive independent charity advocating for real change. We are incredibly grateful for his support and guidance and wish him all the best.

At the same time, we are delighted to introduce Valerie Brisse-Uhlig, our new Chair of Trustees. Valerie has a deep passion for supporting our community. Her leadership will help steer the charity through the next phase of growth and impact. Valerie has been a trustee for 3 years, so she greatly understands the charity's work and needs of the community.

Find out more about Valerie here.

Connecting at the Immunology and Allergy Nursing Conference

Last month, our CEO proudly represented Immunodeficiency UK at the annual Immunology and Allergy Nursing Conference, in Birmingham.

For Immunodeficiency UK, it was a fantastic opportunity to raise awareness of all the resources we have on offer, the challenges faced by those affected, and to discuss collaborative approaches to care. It was an inspiring event allowing us to connect with the dedicated nurses working to improve care for their patients.

A huge thank you to everyone who stopped by our stand — your passion and commitment make all the difference.

Pictured above: Our CEO with Sary Workman, Clinical Nurse Specialist at the newly formed Immunology and Allergy Department at East Kent Hospitals NHS Trust.

Thank you to Grifols and Jeans for Genes

We're incredibly grateful to Grifols for supporting our newsletter for the next year and to Jeans for Genes for their generous core grant funding in support of our work at Immunodeficiency UK. Grants, like these, help us to continue providing trusted information, support services, and advocacy for individuals and families living with primary and secondary immunodeficiencies.

Thanks to their support, we can reach more people, raise greater awareness, and work toward improving care and quality of life for our community.

Your support can change lives – every month

At Immunodeficiency UK, we're here to support people living with primary and secondary immunodeficiency — every step of the way. From the moment of diagnosis through treatment and beyond, we offer trusted information, practical and mental health support, and a listening ear.

But we can’t do it without you.

By setting up a regular monthly gift, you’ll help ensure we can be there for more families, more often. Your support helps us:

- Provide trusted information and support to affected families
- Raise awareness of PIDs among the public and healthcare professionals
- Advocate for improved care and access to treatment

Even £5 a month can make a lasting impact.

Please consider becoming a regular donor today — because together, we can ensure no one faces immunodeficiency alone.

Set Up Your Monthly Gift

Thank you for being part of our community.

It’s not too late to get your COVID-19 vaccination

UK Health Security Agency

NHS

Top up your protection this spring

Those who are immunosuppressed might be eligible for the **spring COVID-19 vaccine offer**

Find out if you’re eligible and book online at **nhs.uk/get-vaccine**

UK Health Security Agency

NHS

Top up your protection this spring

Those with genetic disorders affecting the immune system can take up the **spring COVID-19 vaccine offer**

Book online at **nhs.uk/get-vaccine**

In England: The vaccination programme will run to the 17th of June.
In Scotland: The programme runs to the 30th of June.
In Wales and Northern Ireland. Until the 31st of July.

Visit our webpage for more information.

A mum’s mission for her sons and the immunodeficiency community

When Sophie Hughes crossed the finish line of the Worthing Half Marathon on May 4th, she wasn’t just celebrating 13.1 miles of grit and determination — she was honouring her two sons, Hayden and Jake, who both live with the primary immunodeficiency mannose-binding lectin deficiency.

To channel their experience into something positive, Sophie took on the half-marathon challenge with a modest fundraising target of £200.

But the incredible generosity of friends, family, and supporters soon saw her total soar to an amazing £830 — over four times her original goal!

Thank you, Sophie, for making a difference to families like yours across the UK.

Our recent advocacy activities

Immunodeficiency UK worked with Genetic Alliance UK to support preimplantation genetic testing (PGT) for the rare primary immunodeficiency autoimmune proliferative syndrome (ALPS).

We also sent an independent submission to the Human Fertilisation and Embryology Authority (HFEA) in support. PGT can be used by people who have a serious inherited disease in their family to avoid passing it on to their children. It is a specialised technique that combines in vitro fertilisation technology with genetic testing. The outcome was positive, with the review committee agreeing to authorise PGT testing for ALPS.

We are meeting regularly with NHS England's Strategic Category Management Team, Medicines Procurement and Supply Chain (MPSC) staff to ask questions about how the process of switching of immunoglobulin (IG) products is progressing; what mechanisms are in place to ensure people who for clinical reasons need to remain on the same product, and giving a perspective on the impact of changing product on patients.

Research opportunity – share your workplace experience

Are you living with a chronic health condition, such as a primary or secondary immunodeficiency, and trying to manage work at the same time?

Mila, a researcher from the University of Bath, is looking to speak with people who have faced career disruptions or challenges due to fluctuating physical health. The research explores how chronic illness affects day-to-day experiences in the workplace – including interactions with colleagues, support from employers, and coping strategies.

Would you like to share your story?

Mila is inviting people to take part in a 60-minute one-on-one interview (online via Teams). Your insight could help improve understanding and support for people managing work with a long-term health condition.

Interested?
Please contact Mila at **Mj714@bath.ac.uk** for more information.

Thank you for helping raise awareness of the realities faced by those with chronic and invisible conditions in the workplace.

Finally, we give huge thanks to our amazing community of supporters, families, and individuals living with immunodeficiency. Your continued support makes a world of difference. You inspire us, and we couldn't do what we do without you!

Best wishes,
Susan and Fay
The Immunodeficiency UK Team