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DEFICIENCY
UK

July
Newsletter
2025

# Welcome to the July Immunodeficiency UK newsletter!

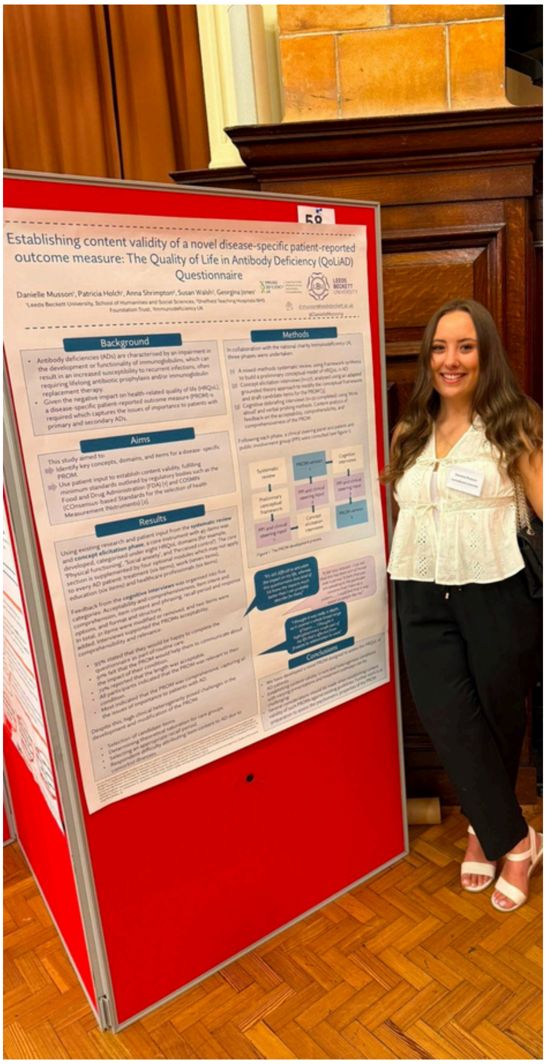
Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we tell you more about Immunodeficiency UK supported research that was presented at an important conference, Hamish shares his CVID diagnosis story and there is an update on COVID-19 and flu vaccination plans.

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.***

# Immunodeficiency UK supported research presented at important conference



Danielle Musson, PhD researcher at Leeds Beckett University, recently presented important work at the annual UK PROMs Conference in Birmingham (pictured left). She showcased a collaborative project between Immunodeficiency UK and Leeds Beckett University.

The project aims to develop and validate a patient-reported outcome measure (PROM) for people living with both primary and secondary antibody deficiency (AD)—a significant step forward, as no disease-specific PROM currently exists for this group.

Danielle's presentation highlighted the impressive progress made so far. The team has nearly completed the development phase of the PROM, which has been shaped by the voices and experiences of immunodeficiency patients:

In phase one, 27 individuals diagnosed with a range of ADs were interviewed to explore how their condition affects their quality of life.

In phase two, a further 23 participants took part in cognitive interviews to evaluate the draft PROM—ensuring it is comprehensive, clear, and meaningful to patients.

Some additional development work will follow, after which the final version of the PROM will be tested through a large-scale survey in partnership with Immunodeficiency UK. This next phase will ensure it is robust and fit for use in both clinical care and research.

This work is especially important because it centres patients' voices and experiences—capturing what truly matters to those living with antibody deficiency. The PROM is designed to support patient-centred care, shared decision-making, and better quality of life outcomes.

We would like to extend our sincere thanks to everyone who has taken part so far. Your insights are helping shape a tool that will make a real difference.

Stay tuned for more updates as the project progresses!

## Run (or walk!) for a cause in 2026

You don’t need to be an athlete to take on the London Landmarks Half Marathon – just the drive to do something amazing for people with immunodeficiency.

🏃‍♂️London Landmarks Half Marathon -April 2026

Our half marathon places offer a spectacular 13.1-mile urban adventure past London's most iconic landmarks.

There is a £30 registration fee and a minimum fundraising pledge of £350.

First-timers are welcome! Ask friends and family if they would like to support a good cause.

Sign up now

# Hamish’s story: My CVID diagnosis

Twenty-three year-old Hamish McLaren went from membership of a grassroots cycling club to achieving a national ranking in road and track cycling. A promising start to a dream career in an elite sport.

But then things started to change for Hamish at around age 15. He began suffering from repeated infections, unexplained fatigue and a noticeable drop in performance.

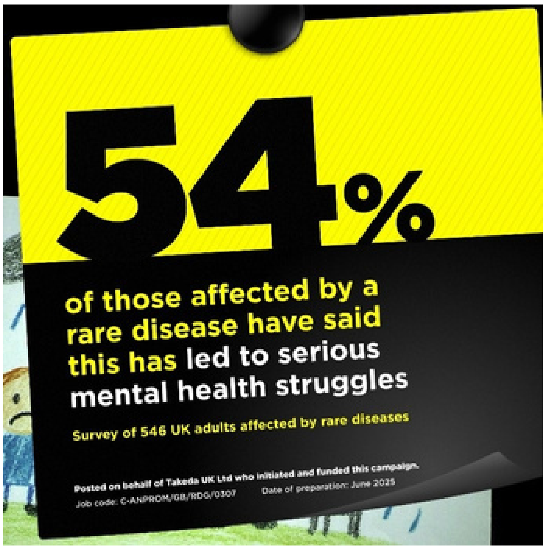
In our latest patient story, Hamish details the diagnosis process he embarked on and what treatment he found useful for managing his CVID. There's even a video from Hamish where he discusses in detail his journey and how his immunodeficiency affected his cycling career.

Read Hamish's story

Would you like to share your own diagnosis story or video? Get in touch with us at fay.fagon@immunodeficiency.org

# Our recent advocacy activities

Immunodeficiency UK provided feedback on the Royal College of Physicians' review of the Quality in Primary Immunodeficiency Services (QPIDS) standards and the Immunoglobulin (IG) demand management plan, as requested by NHS Scotland.



At Immunodeficiency UK, we’re committed to amplifying the voices of those living with rare diseases. That’s why we participated in the #IAmNumber17 campaign—an initiative powered by Takeda to shine a light on the often-overlooked experiences of the rare disease community.

We also signed the #IAmNumber17 open letter to the UK Government, urging greater awareness, support, and action to ensure people with rare conditions receive the care and understanding they both need and deserve.

🔗 Read the open letter here: iamnumber17.org.uk/fridge-diaries

Together, we can raise awareness, spark conversations, and push for lasting change in how rare diseases are understood and supported.

## Update on COVID-19 and flu vaccination plans

The Autumn/Winter vaccination programmes for COVID-19 and flu are on their way. We understand the public will be able to book appointments starting from the 1st of September 2025, with vaccination appointments available from the 1st of October 2025.

**COVID-19 vaccination**

Although exact dates are not yet known, the programme duration is expected to be between the 1st of October 2025 to the 31st of January 2026, with most vaccinations expected to be completed by the 19th of December 2025. You can find updated information on COVID-19 vaccination eligibility at Autumn/Winter COVID-19 vaccination programme 2025 - Immunodeficiency UK.

**Flu vaccination**
- Pregnant women: from the 1st of September 2025
- All other eligible adults, including people with poor immune systems, from the 1st of October 2025
- End of campaign: 31st of March 2026

NHS England recommends that most flu jabs be given by the end of November 2025 to ensure optimal winter protection. You can find further information on flu vaccinations at Flu vaccination programme 2025-2026.

# Plasma news

In this BBC World Service broadcast, journalist Kathleen McLaughlin investigates the multibillion-dollar global plasma industry behind providing immunoglobulin (IG) therapy.

Our patient representative, Hannah Butler, took part, giving her perspective on the importance of IG therapy to her health.

Meet George, a 13-year-old from Bristol who ran 5km every day for 25 days to raise awareness of the importance of blood and plasma donation. George and his younger brother Artie both live with primary immunodeficiency and rely on monthly plasma-derived immunoglobulin infusions.

His mission? To thank donors and inspire 25 new people to donate. He also raised over £2,800 for Bristol Children's Hospital.

Congratulations George.

Read George's inspiring story on the BBC

# How Harry and his friends made a difference

We love sharing uplifting stories from our incredible community — and this one is truly heartwarming.

Eight-year-old Harry, who lives with a primary immunodeficiency, recently led a fundraising effort with his classmates raising £163 to support our work..

Harry and his school friends made colourful loom band bracelets. They decided to sell them to other children at school, turning their creativity into a way to fundraise for Immunodeficiency UK.

When asked why he wanted to take part, Harry's answer was simple:
***I wanted to make money for them because they do so much to help me.***"

Those were his exact words. At just eight years old, Harry's kindness and gratitude are a powerful reminder of the impact our work has — and why it matters.

From all of us at Immunodeficiency UK: Thank you, Harry, and thank you to his wonderful friends, teachers, and everyone who supported their fundraiser. You're helping us continue our mission to support families, fund vital resources, and raise awareness across the UK.

## Wear it with pride – support Immunodeficiency UK in style

Looking for a fun, easy way to show your support for Immunodeficiency UK?

Whether you're fundraising, running a race, or simply want to raise awareness, we've got just the thing.

**Official Immunodeficiency UK T-shirts and running vests**

Designed with comfort in mind, these are perfect for sharing your support in everyday life, sparking conversations and raising awareness.

Best of all, every purchase helps fund our vital work — providing information, support, and advocacy for individuals and families across the UK.
Get yours today https://www.immunodeficiencyuk.org/get-involved/shop/

## Speakers sought for UCL medical school

Dr Hanady Hamdallah, lead for the Patient Pathway and Integrated Community Care module at University College London (UCL) Medical School, is inviting individuals affected by **genetic conditions**—including those living with **primary immunodeficiencies**—to speak with second-year medical students.

“Hearing directly from patients or carers helps our students develop empathy, active listening skills, and a deeper understanding of how genetic conditions impact daily life. It also reinforces the importance of a patient-centred approach to care,” says Dr Hamdallah.

If you or someone you know is living with a genetic condition and would be willing to share their experience, this is a fantastic opportunity to help shape the education of tomorrow’s doctors. UCL will provide full details of the session and will **cover travel costs and provide payment for your time**.

📅 **Session dates:** 6 March and 13 March 2026
📍 **Location:** University College London (details to be provided)

To find out more or express interest, please contact Dr Hanady Hamdallah:
📧 h.hamdallah@ucl.ac.uk or community.meded@ucl.ac.uk

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

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