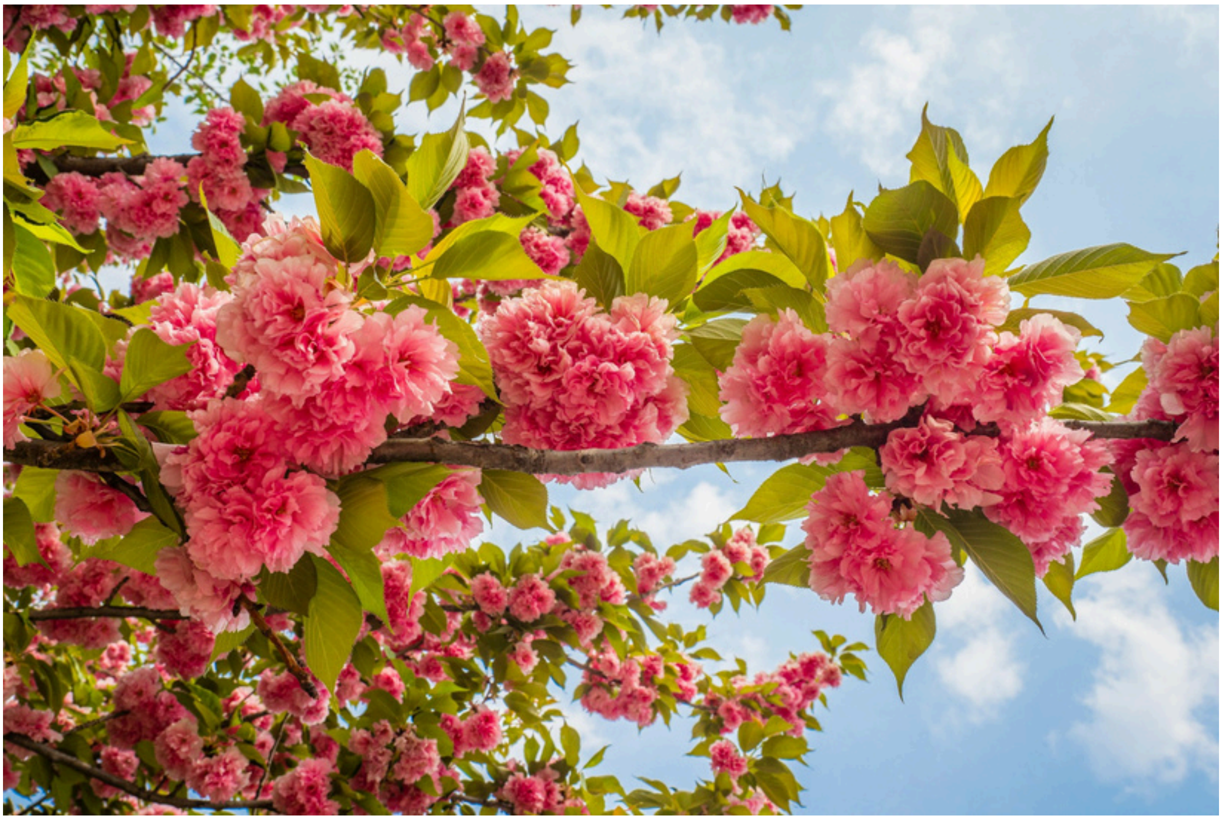
Welcome to the May Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we introduce you to our newest trustee, Graeme shares his story about having CVID and there is some good news about prescription charges.

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

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

Welcome to our new trustee: Tom Taylor

We’re delighted to welcome Tom Taylor to the Board of Trustees at Immunodeficiency UK.

Tom joined us in late 2024 and brings with him a wealth of personal and professional experience.

As someone living with a primary immunodeficiency (PID), he understands firsthand the complex challenges faced by patients, carers, and families—from diagnosis to long-term management.

Professionally, Tom has worked across the NHS and pharmaceutical industry, focusing on the delivery of innovative cell and gene therapies for conditions including cancer, primary immunodeficiencies, and haemoglobinopathies. He’s passionate about advancing access to cutting-edge treatments and strengthening the governance structures that support their safe and effective use.

“I’m really looking forward to supporting Immunodeficiency UK as a new Trustee and providing my skills to support the charity,” says Tom. ***“I hope I can transfer my passion for innovative medicines and strong governance to help drive the charity’s development and growth over the coming years.”***

Tom lives in London with his wife and daughter and is currently under the care of the Royal Free Hospital, having been originally diagnosed and supported at the John Radcliffe Hospital in Oxford.

We’re thrilled to have Tom on board and look forward to the valuable perspective he brings to our work.

Living with CVID: Graeme's journey

Graeme, 38, has lived with Common Variable Immune Deficiency (CVID) since childhood.

Diagnosed at just two years old after months of illness and uncertainty, he now manages his condition with weekly treatment—and a lot of determination.

As a deaf adult navigating both health and communication challenges, Graeme shares how he's adapted his work life, overcome personal hurdles, and learned to advocate for himself.

Read Graeme's full story here:

https://www.immunodeficiencyuk.org/immunodeficiency/patient-stories/stories-of-adults-with-pids/graemes-story

Your story matters— help us raise awareness

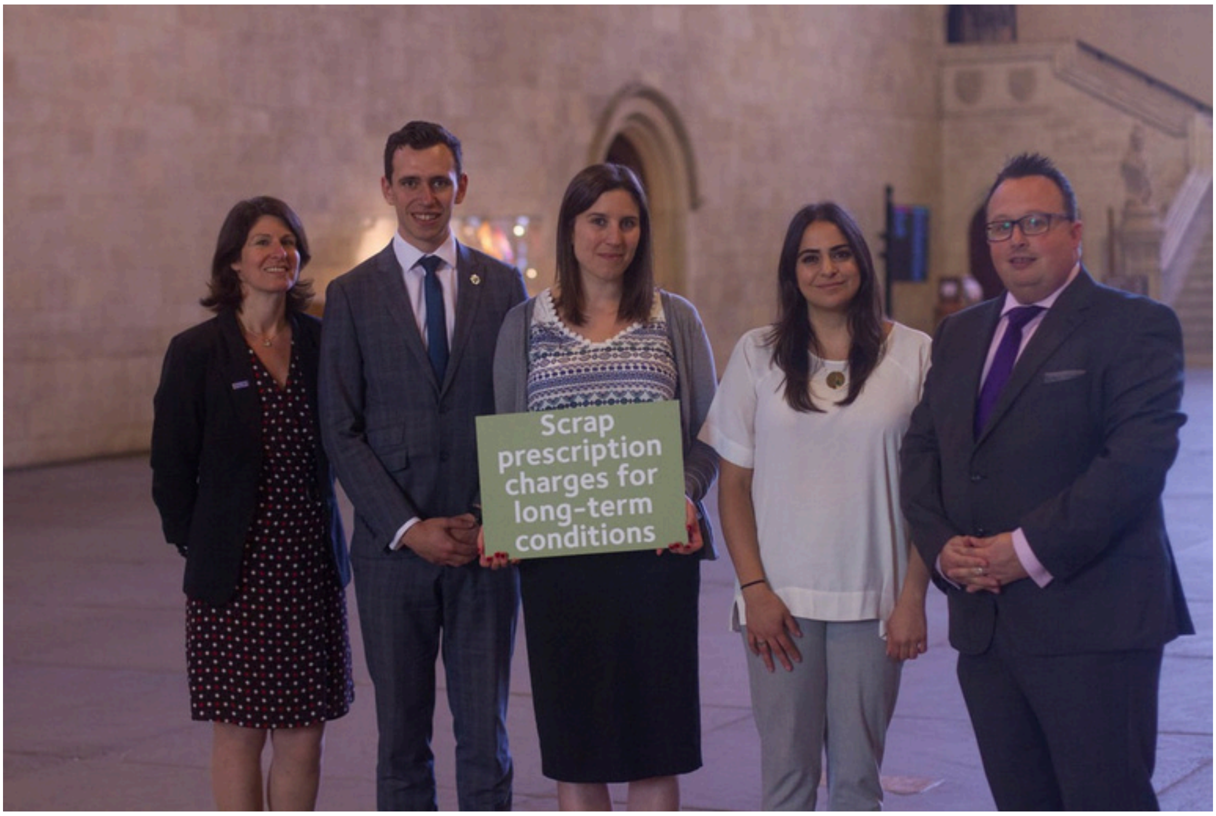
Living with immunodeficiency can be a journey filled with challenges, resilience, and hope—and your story could be the one that makes someone feel less alone.

At Immunodeficiency UK, we believe in the power of lived experience.
Your voice is important.
Ready to share?

Tell us about your experience—diagnosis, treatment, daily life, or how Immunodeficiency UK has helped you. We'll support you in shaping your story for our website, newsletters, or social media.

Get started by sending us an email at fay.fagon@immunodeficiencyuk.org

Prescription charges frozen—but more needs to be done



There's some good news: prescription charges in England will be frozen for 2025–26. The single item charge will remain at £9.90, and the cost of 3-month and 12-month prepayment certificates will also stay the same. Existing exemptions continue to apply.

However, the criteria for medical exemptions have remained largely unchanged since the 1960s. As a result, nearly three million people in England with long-term health conditions—including many affected by immunodeficiency—still do not qualify for free prescriptions.

That's why Immunodeficiency UK has joined 50 other organisations in calling on the Government to scrap prescription charges for people living with long-term conditions in England.

We believe no one should have to face financial barriers to access essential medication. Learn how you can get involved in the campaign at https://www.prescriptionchargescoalition.org.uk/take-action.html

Switching immunoglobulin products in 2025

The NHS has issued guidance to support patients through this process, including details on safety, what to expect, and how switching will be managed.

Read their full patient information here:
Switching immunoglobulin products under the new framework in 2025 (PDF)

Have your say in the future of childhood bone marrow transplant (BMT) research!

We're proud to support the Murdoch Children's Research Institute and their international project, "Big Ideas for Little Lives," shaping research priorities for childhood BMT.

Survey 2 is NOW OPEN!

667 questions were submitted in the first phase. Now, it's your turn to vote on the most important ones.

Your voice will help focus future research on the topics that can make the biggest difference to children undergoing BMT.

Whether you’re a parent, young adult, carer, or healthcare professional—you can help guide change.

Open until 2 June 2025

Take the survey here: https://redcap.mcri.edu.au/surveys/?s=FJF3JCPKY33A7KL8

Mental health awareness week: supporting wellbeing in the immunodeficiency community

At Immunodeficiency UK, we know that mental health matters—especially for those living with primary and secondary immunodeficiencies. The emotional toll of chronic illness can be just as real and overwhelming as the physical symptoms. So, this Mental Health Awareness Week, we are sharing what we are doing to support the immunodeficiency community.

Here’s what you told us:

88% of our community say their condition negatively impacts their mental health

80% want access to mental health support through Immunodeficiency UK

We heard you—and we acted.

Mental health webinars— created with you in mind

In partnership with RareMinds, we launched a series of dedicated mental health webinars designed to address the challenges of living with immunodeficiency and the most recent one took place last month.

Feedback from participants

“It was good to hear other people’s situations and also how to cope with emotions and feelings around diagnosis of our rare illnesses.”

“The session has shown us coping mechanisms, and Rebecca gave us all personal ideas we can implement to help improve our situations. Rebecca was excellent and included everyone to make us all feel welcome. I found it a great course and well worth attending. I don’t feel so alone in my diagnosis now.”

Looking Ahead

Mental health support is not a one-off. It’s a priority.

We’re committed to expanding our mental health resources and ensuring emotional wellbeing remains at the heart of our work.

Together, we’re building a stronger, more supported community.

Help us make a difference

Every person living with immunodeficiency deserves the right support at the right time. But we can't do it without you.

Whether it’s a bake sale, charity run, quiz night, or birthday fundraiser, your efforts help us provide life-changing support, raise awareness, and push for better care for those affected by immunodeficiency.

Be part of something bigger

Getting involved is easy, and we’re here to help you every step of the way—with fundraising resources, tips, and personalised support to make your event a success.

Whether you raise £20 or £2,000, every pound brings us closer to a future where no one faces immunodeficiency alone.

Start your fundraising journey today: www.immunodeficiencyuk.org/get-involved/fundraising

STRAVINSKY study - update

Watch the webinar that took place on 6 May 2025, in which STRAVINSKY study lead Professor Alex Richter gives an update on progress so far with the project and the next steps as the study comes to a close.

Watch the webinar

Best wishes,

Susan and Fay

The Immunodeficiency UK Team