

### October Newsletter 2025

### Welcome to the October Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we are asking you to share your experience of IG therapy through our newly launched survey. In this edition we also cover a new report on a staffing crisis in immunology services and share a new guide for university and college students.

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

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

# Share your experience of immunoglobulin (IG) therapy



Whether you've already switched your IG product or been informed that a change is on the way or not been switched, we want to hear your views on the management of IG product availability.

Your feedback will help ensure that future NHS decisions better reflect the real needs and preferences of patients and families.

Please take time to do our short, anonymous survey exploring how people are being affected by recent changes to the availability of different IG therapy products.

Who can take part:

Anyone living or caring for someone in the UK with a primary or secondary immunodeficiency who is currently receiving IG therapy.

- Takes just 10–12 minutes
- Completely anonymous

#### Take the survey

Thank you for helping us shape a better future for the immunodeficiency community.

## Crisis in immunology services puts patients at risk



A new report from the Royal College of Pathologists warns that immunology services across the UK are at breaking point. With staff shortages, unfilled consultant posts, and looming retirements, patients with immunodeficiencies face delays in diagnosis, disrupted treatment, and reduced access to specialist care.

The report calls for urgent action, including more training posts, investment in diagnostics, and stronger workforce planning.

The report found that 39% of immunology services have at least one consultant vacancy, over half unfilled for a year or more. A quarter of services currently rely on just one consultant immunologist, leaving them highly vulnerable to collapse. The situation is set to worsen, with 21% of consultant immunologists expected to retire within five years — many earlier than planned due to burnout and poor work-life balance.

### Dr Patrick Yong, Chair of the College Specialty Advisory Committee for Immunology, said:

"This is a sobering report. Consultant immunologists are incredibly dedicated to their patients and most services are relying on goodwill – unpaid overtime – to keep services running. This isn't the way to provide safe, effective patient care. As well as establishing more training posts, we must focus on ways to retain the experienced consultants we have."

"This report is a wake-up call. Every day, people with immunodeficiency are waiting too long for answers. We need urgent action to protect this community and ensure patients aren't left to face these conditions without timely care." Dr Susan Walsh, CEO, Immunodeficiency UK

#### Read the full report on our website

If staff shortages are affecting your care at your immunology centre, then please contact us and share your experience at <a href="mailto:hello@immunodeficiencyuk.org">hello@immunodeficiencyuk.org</a>.

# Heading to university or college with immunodeficiency?



Starting university or college is an exciting step — but for young people with an immunodeficiency, it can also bring unique challenges. From transferring treatment to a new hospital and arranging accommodation to registering with student support services, planning can make all the difference.

On our website, you'll find practical advice, tips, and real student stories to help you prepare and feel confident about this big step towards independence.

Read more on our website

# Immunodeficiency UK at the East of England Regional Immunology and Immunoglobulin Educational Day



Pictured: Rich Collins, CEO of Inflammatory Neuropathy UK, Karen Henderson,
Immunoglobulin Clinical Nurse Specialist/East of England Immunoglobulin Assessment Panel, our CEO Dr
Susan Walsh and David de Monteverde-Robb, Lead Pharmacist, East of England Immunoglobulin
Assessment Panel.

We're delighted to announce that our CEO recently spoke at the East of England Regional Immunology and Immunoglobulin Nursing and Pharmacist Educational Day, which took place on 16th October 2025 at Madingley Hall, Cambridge.

This annual event brings together nurses, pharmacists, and specialists from across the region to share best practices and strengthen support for patients requiring long-term immunoglobulin therapy — including those living with primary and secondary immunodeficiency and neurological conditions.

The day provided an invaluable opportunity for education, networking, and collaboration. This year's focus was on revisiting the patient experience, highlighting the vital role of patient perspectives in shaping high-quality, compassionate care.

Our CEO, Susan gave a presentation, giving insights and reflections from our charity's experience working closely with patients and healthcare professionals in this field. 'We were proud to be part of this important conversation and to support ongoing efforts to improve outcomes and experiences for individuals receiving immunoglobulin therapy'.

# Raise funds for Immunodeficiency UK every time you shop online



Did you know you can support Immunodeficiency UK just by doing your everyday online shopping?

Through easyfundraising, over 7,000 retailers will donate a percentage of what you spend—at no extra cost to you. The brands cover the donation, so it's completely free.

#### Here's how it works:

- 1. Sign up for free at easyfundraising.org.uk/causes/immunodeficiencyuk.
- 2. Start your shop via easyfundraising to choose your retailer.
- 3. Complete your purchase as normal, and the retailer donates to Immunodeficiency UK!

For the easiest way to support us on your phone, download the #easyfundraising app — it's completely FREE and available on iOS and Android. Start shopping today and never miss a chance to raise vital funds for Immunodeficiency UK!

https://www.easyfundraising.org.uk/easyfundraising-app/

Thank you for supporting our work.

Start shopping today →

### Take on 26.2 miles, your way — join Team Immunodeficiency UK



Be part of one of the world's most iconic races — from anywhere!

Join Team Immunodeficiency UK for the Virtual TCS London Marathon and complete your 26.2 miles on your own route, at your own pace, on Sunday, 27 April 2026. Whether you run, jog, or walk, you'll be helping us support children and adults living with primary and secondary immunodeficiency across the UK.

Every step you take helps us raise awareness, fund vital resources, and provide hope to families facing daily health challenges.

#### You'll receive:

- Fundraising support every step of the way
- The chance to make a real difference from wherever you are

Places are limited — don't miss your chance to take part in this unforgettable challenge.

Join Team Immunodeficiency 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