



## Welcome to the January Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the first newsletter of 2025. We hope you had a great festive season and that you find the information in this newsletter useful.

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.***

## A massive thank you



Thank you to our amazing community for the generous donations we received during our Giving Tuesday and Christmas fundraising campaign. Your support for the charity is truly special, and we want to take a moment to express our heartfelt thanks.

Your generous contributions will go directly towards providing essential support and resources for those living with immunodeficiency.

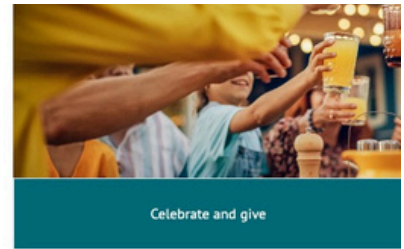
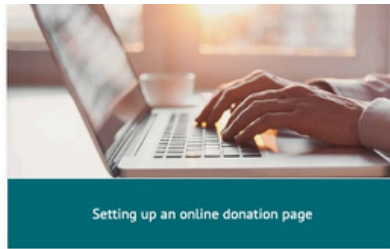
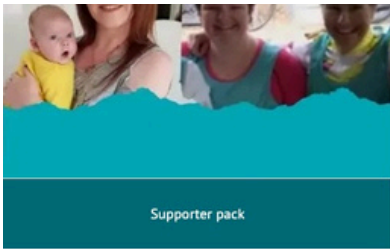
***"Thank you for your speedy response. As always, you give clear, helpful advice, for which I am very grateful." From a recent helpline user.***

As we step into the new year, we're excited to continue our work supporting people with primary and secondary immunodeficiency. Together, we can make a difference.

Thank you once again for your incredible generosity and kindness.

Wishing you a joyful, healthy, and peaceful 2025!

# Make 2025 a year of impact: fundraise for us!



2025 is now upon us, and we're inviting you to make it a year to remember by fundraising for Immunodeficiency UK. Every step, bake sale, or event helps us to continue supporting individuals living with immunodeficiency and their families.

Whether you're a seasoned fundraiser or trying something new, we're here to help. From challenge events to workplace fundraisers, there's a way for everyone to get involved. Need inspiration or resources? Check out our fundraising ideas and download our supporter pack to get started.

Let's make 2025 a year of generosity, community, and change. Together, we can make a lasting difference. Visit our fundraising page for more ideas, inspiration and resources.

## Thank you Jim



Pictured: Jim Carvell (on the left) and Michael Ingleston

Jim Carvell, a long-time supporter of Immunodeficiency UK, recently celebrated his 80th birthday at The Stables restaurant in Groomsport, Co Down.

Michael Ingleston, a member of our Patient Representative Panel, was delighted to be among the twenty-five close family and friends invited.

Guests had been asked to consider making a donation to Immunodeficiency UK instead of buying birthday presents, and this raised a total of £560! It was a great afternoon's 'craic' as some of the many friends Jim has made through the years chatted and enjoyed a meal together.

Immunodeficiency UK is very grateful to Jim and his wife Heather for their generous support and wishes him many happy returns.

## The non-patient-facing role that supports immunology services



Pictured: Joshua with his wife and daughter.

Joshua Kenney, a trainee clinical scientist working within the immunology department at University Hospital Leicester contacted us last year to learn about the charity's support for people living with immunodeficiency. We in turn asked him about his chosen profession and how it helps people with immunodeficiency.

Here is his story: 'I'm in my final year of a 3-year NHS-funded clinical scientist (CS) training programme called the STP (Scientist Training Programme). As well as the laboratory training, I'm also studying part-time for an MSc in Clinical Science, specialising in immunology, at the University of Manchester. To complete the STP, I must complete multiple training activities in areas of immunology, including immunodeficiency, autoimmunity, allergy, and haematological oncology.

Working as a CS is highly varied, challenging, and rewarding. They contribute significantly to the diagnosis, monitoring, and management of primary (PID) and secondary immunodeficiency (SID) patients through clinical authorisation of laboratory results. They have responsibility for escalating clinically urgent findings to clinicians, such as treating a newly suspected case of severe combined immunodeficiency (SCID) as a paediatric emergency.

A CS is involved in both quality and service improvement, ranging from evaluating in-house internal and external quality control to ensure the tests conform to UKAS standards, to the introduction of new or improved testing pathways. For example, our laboratory now has brand-new cell analysers allowing us to improve our immunodeficiency tests, providing a much better prognostic and treatment overview for clinicians and patients.

The role is highly collaborative, with the immunology team working closely with other specialities, such as haematology and rheumatology, regarding the referral of new patients or making clinicians aware of clinically urgent results.

They also work closely with other service users, including GPs, to inform them of any significant changes or updates to the tests they offer. Sometimes, they train new medical staff in the interpretation of lab results.

We work within the hospital's pathology network at the hospital; e.g., immunology collaborates with departments such as biochemistry, special haematology, and genetics. This ensures that collectively, we are all continuing to work to an accredited high standard.

Of course, working in the NHS, there are the pressures of a heavily increasing workload whilst managing a department with limited financial resources and staff. Alongside this, there's a need to balance these ongoing concerns with other important responsibilities, usually involving service and quality improvement, and these can often be time-consuming and highly complex.

Being a CS is not primarily a patient-facing role and is more aligned with the daily operations of the laboratory. Through training, I've come to appreciate the significant impact immunodeficiency can have on patients and their families, having had the opportunity to attend clinics and speak with patients directly. This provided me with a better perspective on the role CS's have working in the laboratory on the diagnosis, treatment and management of these patients.

***"I am extremely grateful for Dr Susan Walsh taking the time out of her busy schedule to meet with me to discuss the daily operations and running of Immunodeficiency UK. Susan was very accommodating, especially with all the questions I asked, and was kind enough to send me a selection of information booklets that I can distribute to staff in the laboratory. I shall be taking what I have learnt about charity's role in helping people with immunodeficiency and presenting it back to staff within my department to hopefully raise better awareness. I want to ensure those working in the department who are not typically patient-facing know about the critical and positive work they do in providing support and advice to patients and families."***

We'd like to give huge thanks to Josh for telling us about his job and for raising awareness and wish him every success in his exams.

Thank you to our 2024 sponsors

# Thank You

We would like to give a big shout out to the following sponsors who helped support our work:

**CSL Behring**  Pharming

**GRIFOLS**



Their support has been vital in helping us provide essential resources and support for people affected by immunodeficiency.

From everyone at Immunodeficiency UK, thank you.

# Updated service specification for specialist immunology services



In December 2024, NHS England published an updated service specification for specialist immunology services for adults with deficient immune systems. It defines the standards of care expected from organisations providing specialised care and describes the patient pathway: diagnosis, treatment and monitoring and linkage with other health services. The specification was developed by specialised clinicians, commissioners, expert patients and public health representatives.

Immunodeficiency UK was involved in providing stakeholder feedback.

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We hope you all had a wonderful Christmas and have had a great start to 2025.

Best wishes, Susan and Fay

The Immunodeficiency UK Team

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