



## Welcome to the July Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the July newsletter. We hope you find the information useful to you.

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.*

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## A new Immunology service for Kent



(On the left is Karen Edmunds, Associate Director of Patient Experience and on the right is Dr Lemana Mutlu who will be leading the immunology service).

East Kent Hospitals University NHS Foundation Trust (EKHUFT) are launching a new immunology and allergy service for Kent.

They have appointed Dr Lemana Mutlu who is a consultant immunologist and allergist to set up the service. Dr Mutlu joined the trust after completing her training in Birmingham with her mentor Dr Aarnoud Huissoon. They are also recruiting a clinical specialist nurse to work as part of the team.

Initially the service will focus on patients with secondary immunodeficiency and severe allergies but will also look to support patients with primary immunodeficiency in due course. Arrangements are planned for people who are already receiving immunoglobulin to access the nursing care and support.

As this is a new service, they are keen to involve patients from the start, so that it can be a truly co-designed service that puts patients at the centre of the support and care provided.

Karen Edmunds, Associate Director of Patient Experience said, "as an East Kent resident living with primary immunodeficiency and on immunoglobulin therapy, this is an exciting development and in my role at the Trust myself and our team

are here to make sure patients and their families have not only a voice, but also shape how our services are developed and delivered.”

Susan Walsh, CEO of Immunodeficiency UK, who said: ‘This is wonderful news for people affected by primary immunodeficiency living in Kent. Having a specialist clinic nearer to home will save people time and the cost of travel’

If you are a Kent resident, living with immunodeficiency and on immunoglobulin therapy, the Kent team would love to hear from you! Please contact the Patient Voice and Involvement team by email: [ekhuft.patientvoice@nhs.net](mailto:ekhuft.patientvoice@nhs.net) or phone 01227 868605.

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## Supporting Employees with Immunodeficiency



Under the Equality Act 2010, individuals with immunodeficiencies are protected from discrimination. Employers must make reasonable adjustments to ensure they are not substantially disadvantaged.

This duty applies to all workers, including trainees, apprentices, contract workers, and business partners.

Often, people with an immunodeficiency do not need any workplace adjustment, but some individuals may have complications related to their condition that requires a flexible approach to working or changes to the work environment.

For example, an individual may have a higher risk of becoming seriously ill from respiratory infections, requiring mitigating measures in the workplace. Another may have specific needs, such as hearing impairment. A person with immunodeficiency may need regular infusion treatments and so a flexible work pattern can allow them to attend appointments without affecting productivity.

Immunodeficiency UK offers a downloadable letter to help communicate these responsibilities to employers. This resource is designed to clarify the importance of supporting employees with immunodeficiencies and to guide employers in making the necessary adjustments.

For more information and to download the employer support letter, [visit the website](#).

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## Empowering Our Community: Know Your Employment Rights!



At Immunodeficiency UK, we are dedicated to supporting individuals and families affected by immunodeficiency. Ensuring you are well-informed about your employment rights is a crucial part of this support.

With this in mind we created a leaflet, "Your Employment Rights," tailored specifically for those with immunodeficiency. It provides essential information to help you navigate the workplace confidently and assert your rights.

### **Key Highlights from the Booklet**

**\*\*Protection Against Discrimination\*\***

**\*\*Reasonable Adjustments in the Workplace\*\***

**\*\*Redundancy and Sickness Absence\*\*** **\*\*Flexible Working Options\*\***

[Visit our website to download your copy today!](#)

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## **Helen's Skydive Fundraiser for Immunodeficiency UK**



Helen has already raised an incredible £1,010.00, plus an additional £252.50 in Gift Aid, for a cause very close to her heart.

Her three-year-old grandson has a rare condition that prevents him from making his own antibodies, relying on weekly immunoglobulin replacement therapy.

To support Immunodeficiency UK, Helen took a truly brave leap—quite literally. On July 6, 2024, she jumped out of a plane from 13,000 feet, despite her fear of heights. Strapped to an experienced instructor, Susan's courageous skydive symbolises her commitment to our cause.

Thank you Helen for helping Immunodeficiency UK continue their vital work.

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## Tips for staying safe in the sun



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We are hopeful that the summer weather will improve where you are. So just in case here are some top tips for coping with heat when temperatures rise:

- Stay hydrated - drink plenty of water
- Keep your home cool - close curtains, open windows at night
- Avoid direct sun, especially 11am-3pm
- Wear light, loose clothing

- Take cool showers or baths
- Check your medications - some may be affected by heat

For more tips on coping with hot weather, check the NHS advice: <https://www.nhs.uk/live-well/seasonal-health/heatwave-how-to-cope-in-hotweather>

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## Accessing free LFT's



COVID cases are rising. For those needing lateral flow tests (LFTs), nhs.uk has launched a [new pharmacy finder](#). This tool helps you locate pharmacies offering free LFTs if you're eligible for COVID-19 treatments.

This should make it easier for you to locate a nearby pharmacy that offers the service. Further information on COVID-19 treatments and how to access the service can be found at [www.nhs.uk/COVIDtreatments](http://www.nhs.uk/COVIDtreatments).


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## Join Team Immunodeficiency UK for the London Landmarks Half Marathon 2025!



Are you ready for an unforgettable running experience through the heart of London? We're thrilled to announce that Immunodeficiency UK has secured places for the iconic London Landmarks Half Marathon 2025!

 Date: 6 April 2025 (TBC)

 Location: Starting at Pall Mall, London, SW1

### Why run with Team Immunodeficiency UK?

- Make a difference: Raise vital funds to support individuals living with immunodeficiency in the UK
- Guaranteed entry: No need to worry about the ballot!
- Explore London: Run past iconic landmarks like Big Ben, the London Eye, and Buckingham Palace

By joining our team, you'll not only challenge yourself but also help raise awareness for immunodeficiencies. Your efforts will directly support our essential services for patients and families affected by these often-overlooked conditions.

Whether you're a seasoned runner or a first-timer, this is your chance to be part of something extraordinary. Sign up today and secure your spot on Team Immunodeficiency UK! More information [here](#).

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## Enhancing Mental Health Support



## Wellbeing Hub

Resources and information to help you live as well as possible with your rare condition



At Immunodeficiency UK, we recognise that living with an immunodeficiency affects both physical and mental wellbeing. And that is why we are collaborating with Rare Minds to enhance our mental health support services for individuals with immunodeficiencies and their carers.

As part of our commitment to holistic care, we want to highlight a valuable resource that may benefit our community:

### Rare Minds Wellbeing Hub

Our friends at Rare Minds, have created a new online Wellbeing Hub for the rare disease community. This resource offers information and support on a wide range of topics relevant to those living with rare conditions, including immunodeficiencies. Access it [here](#)

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## Attention Immunodeficiency UK supporters!



The Yorkshire Building Society Charitable Foundation is offering grants of £250-£2,000 for UK charities improving health and saving lives. This could be a great opportunity for Immunodeficiency UK!

To apply, we need a Yorkshire Building Society member or colleague to nominate us.

Do you or someone you know bank with the Yorkshire Building Society? Your nomination could make a big difference! Help us continue supporting those with

primary and secondary immunodeficiencies. Spread the word and let's secure this funding together!

**An online Charitable Foundation Member Nomination form can be found [here](#).**

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Best Wishes,  
Susan and Fay  
The Immunodeficiency UK Team

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