



June  
Newsletter

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## Welcome to the June Immunodeficiency UK newsletter!

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Hello Immunodeficiency UK member, we hope you are keeping safe and well and welcome to our June newsletter. We hope you will find it informative.

Read on for our monthly news round up and, don't forget to [like us on Facebook](#) to get updates throughout the month.

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### COVID-19 vaccine Spring booster



A quick reminder - if you're eligible for a spring booster dose of the COVID-19 vaccine, the last date you'll be able to get vaccinated is 30 June 2023. The medical advice remains to keep up to date with the vaccinations as you may receive some protection.

Later this year the NHS will contact you if your NHS record suggests you may be eligible for a further seasonal booster.

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## COVID-19 surveillance



Charities still haven't had a response to our [joint letter](#) to Dame Jenny Harries at The UK Health Security Agency concerning COVID-19 surveillance and we are continuing to push for a response.

In the meantime, a slimmed-down variant [monitoring briefing](#) has been introduced and the Office for National Statistics has launched a [COVID-19 and Respiratory Infections Survey \(CRIS\)](#). This survey is accessible by invitation only and aims to understand and manage COVID-19 and other respiratory infections in the long term within the NHS.

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Help improve the COVID-19 booster service and receive  
a £25 shopping voucher



The NHS and Hertfordshire County Council are working together to understand the experiences of individuals with weakened immune systems in relation to the COVID-19 booster vaccine. The group says 'Your experiences are important in

guiding us towards better services and can make a real difference in shaping healthcare.’

They would like to hear from you if you are:

- Over 18 years old
- Are immunocompromised or immunosuppressed
- Access care in the East of England.

You can share your thoughts through a quick survey:

<https://surveys.hertfordshire.gov.uk/s/ServiceImprovement/>

OR:

Take part in an online interview and receive a £25 voucher (for each completed interview): <https://surveys.hertfordshire.gov.uk/s/InterestforInterviews/>

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## Change of access to COVID-19 medicines in England

Since December 2021, COVID-19 treatments have been offered through a nationally commissioned service to people who are at the highest risk of becoming seriously ill and test positive in the community. This service was delivered through COVID Medicines Delivery Units (CMDUs). It was set up under pandemic-specific arrangements and currently uses a common care pathway that applies nationally.

As of the 27th June 2023 the access to COVID-19 treatments will change and regional Integrated Care Boards (ICBs) in England will take over these services for their areas. ICBs must provide this access service but the way it is delivered is likely to differ from one ICB to another.

If you were previously eligible for COVID-19 medications, you should receive a letter from the 5th June to update you on the changes. Visit <https://www.england.nhs.uk/coronavirus/patient-letter> for easy read, large print, braille and translated versions for those people that require them.

On the 27th June access to COVID-19 medicines will follow the [final guidance by NICE](#), that states people with a weakened immune system, aged 12 and above, who test positive for COVID may be eligible for Paxlovid (nirmatrelvir/ritonavir) (antiviral, tablets) or sotrovimab (antibody, intravenous drip), if Paxlovid is unsuitable.

NHS England have informed us that:

'As we are unable to provide specific details for each patient's local access arrangement, the letter will instead advise patients to contact their GP, NHS 111 or hospital specialist following a positive test.'

'From 27 June onwards, queries about the service should be directed to the relevant ICB in the first instance and you can find their contact details on the [ICB Finder](#).'

NHS England has also told us that national communications are planned during June with bulletins to GPs, 111 and specialists, and that ICBs will be planning their own locally-led communications to these services.

You can find a Q&A on the changes at [Access to COVID19 therapeutics Q and A for stakeholder patient enquiries.docx \(live.com\)](#)

Points to remember:

- The [existing mechanisms to access COVID-19 medicines](#) remain in place until the 27th June.
- After the 27th June if you live in England you will NOT be contacted automatically by NHS England about access to COVID-19 treatments if you register a positive COVID-19 test. The general advice is to contact your GP practice, NHS 111 or hospital specialist as soon as possible after you test positive so that they can consider referring you for an assessment for treatment.
- There are 42 ICBs and implementation in each ICB catchment area may vary. This will make it almost impossible for Immunodeficiency UK to advise on the specific access pathways and at present we can only say that your local GP should know what the arrangements are in your area.
- For the devolved nations, Northern Ireland, Scotland and Wales, we are keeping a watchful eye on any planned changes.

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 **Congratulations, Deborah and the Mummy's Little Bistro Team!** 

We are thrilled to share some exciting news with you all. Deborah and her incredible colleagues from Mummy's Little Bistro in Belfast have successfully completed a heart-stopping abseil down the iconic Europa, raising £640 for Immunodeficiency UK!

They fearlessly descended from great heights, all in the name of supporting three remarkable charities, one of which is Immunodeficiency UK. Let's take a

moment to applaud their tremendous effort and the positive impact they have made.

We would like to extend our heartfelt gratitude to Deborah and the entire Mummy's Little Bistro team for their brilliant fundraising. Your willingness to step out of your comfort zones and take on this incredible challenge is truly commendable.

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## Support Joe and Lesley's Immunodeficiency UK Virtual Challenge

We have some extraordinary supporters among us who are always ready to go the extra mile for Immunodeficiency UK. Today, we want to shine a spotlight on Joe and Lesley, who are taking part in the "Choose Your Own Distance" Immunodeficiency UK Virtual Challenge. They are embarking on a personal journey to raise funds and awareness for our work, and they need our support!

They have decided to step up and make a difference in the lives of those living with immunodeficiency. They are determined to push their limits and complete a challenging distance of their choice, all in support of our work. By participating in this virtual challenge, they are not only raising vital funds but also spreading awareness about the challenges faced by those with immunodeficiencies.

We all have the power to make a difference, and today we are reaching out to our generous community to help support Joe and Lesley's efforts. Here's how you can contribute and show your support:

1. Visit [Joe's JustGiving page](#) and make a donation. Every contribution, no matter how big or small, will make a meaningful impact on the lives of those affected by immunodeficiency.
2. Head over to [Lesley's JustGiving page](#) and show your support by making a donation. Let's rally together and help them achieve their fundraising goals.

Remember, it's not just about the amount of the donation, but the collective power of our support. Every pound will help Immunodeficiency UK provide essential resources, support, and care for individuals and families affected by immunodeficiency.

And don't forget there's still time for you to sign up for our 'Choose your own distance' fundraising challenge as it is running until the end of June. Sign up [here](#).

Together, we can make a real difference in the lives of those who need it most.

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Best Wishes,  
Susan and Fay  
The Immunodeficiency UK Team

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Immunodeficiency UK | Immunodeficiency UK, PO Box 12635, Colchester, CO7 5AN

**Jenny Rush**

Authorized representative: Jenny Rush | Email: [jen.rush@immunodeficiencyuk.org](mailto:jen.rush@immunodeficiencyuk.org) | Charity Number: 1193166.

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