



July  
Newsletter

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Welcome to the July Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member, we hope you are keeping safe and well.

Read on for our monthly news round up and, as always, please don't hesitate to get in touch if you have any questions or comments.

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## COVID-19 – information on the Autumn booster and vaccination programme



Joint Committee on Vaccination and Immunisation (JCVI) has now published its [final recommendations](#) for this autumn's programme. The final eligible groups are now broader than those announced in the JCVI's interim advice in May. The booster programme will be running in all four home nations.

Under the advice, those eligible for a further dose will be:

- Residents in a care home for older adults and staff working in care homes for older adults
- Frontline health and social care workers as defined in the [Green Book](#)
- All adults aged 50 and over
- Those aged 5 to 49 years in a clinical risk group, including pregnant women. Clinical risk groups are defined in Table 3 (16 years and over; page 16) and Table 4 (aged 5 – 15 years of age; page 22) of the [Green Book](#) and includes people who are immunosuppressed due to disease, e.g. having a primary or secondary immunodeficiency or due to treatment e.g. taking immunosuppressive or immunomodulating biological therapy.
- Those aged 5 to 49 years who are household contacts of people with immunosuppression
- Those aged 16 to 49 years who are carers. The definition of carers aged 16 to 49 years is set out in the [Green Book](#) – Table 3 (page 17).

The committee considered the recent epidemiology of the BA.4 and BA.5 waves, as well as the benefits of aligning the COVID-19 programme with the flu vaccine rollout, concluding that expanding the offer would provide necessary protection to those at higher risk of severe illness and keep greater numbers of people out of hospital.

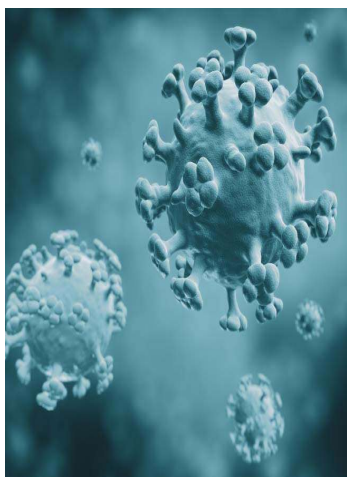
All eligible groups are encouraged to take up the vaccine when it is offered, even if they have had a spring booster, to give themselves the best possible protection against COVID-19 this winter.

Immunodeficiency UK has been told that the NHS will announce in due course when and how eligible groups will be able to book an appointment for their COVID-19 autumn booster.

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## Flu vaccinations

In addition, the Department of Health and Social Care (DHSC) will once again be offering the free flu vaccine to additional groups. These additional groups, see below, will only be eligible once the most vulnerable, including previously announced pre-school and primary school children, those aged 65 years and over and those in clinical risk groups (as defined in the [Green Book](#); as above), have been offered the jab.



The additional groups set to be offered the free flu vaccine in England will be:

- All adults aged 50 to 64 years
- Secondary school children in years 7, 8 and 9, who will be offered the vaccine in order of school year (starting with the youngest first)

The flu vaccine programme outlined above applies to England only, we have yet to learn about the flu vaccination programmes in other home nations.

Immunodeficiency UK has been told that the NHS will announce in due course when people aged 50 to 64 years old who are not in a clinical risk group will be able to get their free flu jab. People in these groups are asked not to come forward until further information is announced.

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## Evusheld - Daisy Cooper MP and Tom Pearman call for access on BBC Three Counties Radio



On the 13th July, Daisy Cooper, MP for St Albans (pictured left), and Tom Pearman (pictured right), who has CVID, took part in a Three Counties Radio interview on the Andy Collins show calling for access to Evusheld.

In the interview Daisy, who has been lobbying for access to Evusheld since January 2022 following contact by a CVID patient in her constituency, described the situation as ‘frustrating’, citing the lack of transparency of government decision making and the ongoing dispute with the government over the evidence of its efficacy and how much evidence is needed to prove its efficacy, before the government will procure stock.

Tom, who has COVID, shared his experience of living with the threat of COVID, 'our lives are on hold', and why access to Evusheld is so important and described it as 'a massive opportunity for people to get their lives back'. You can listen to the 11-minute interviews at this [link](#) – the discussion on Evusheld starts at 1:06:53. It's worth a listen.

You can find a recent response from the government on Evusheld [here](#).

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## Appeal for adult volunteers with X-linked Hyper IgM to contribute to clinical research in Milan

The Hyper IgM Foundation is working to drive research forward into new treatments for X-Linked Hyper IgM Syndrome. In March this year, they helped Chris Sheasby, an adult X-Linked Hyper IgM patient living in Cambridge, to donate T-cells to research conducted by Drs. Canarutto and Ferrua in Milan, Italy, on gene editing for Hyper IgM Syndrome. Chris has written a [blog](#) about his experience volunteering.

Hyper IgM Syndrome is such a rare condition; the Milan research team has had to draw on the help of volunteers from far and wide. But they still need many more volunteers to progress through the final stages of their research so that hopefully, before long, they can commence their clinical trials for gene therapy. To support this important research in Milan, working on cutting-edge new T cell gene editing, The Hyper IgM Foundation will cover all costs associated with travel and lodging in Milan. Please contact [research@hyperigm](mailto:research@hyperigm) for more information.

If you would like to find out more about Hyper IgM syndrome then take a look at our [booklet](#).



Chris' first ever selfie just after he had finished my consultation at San Raffaele Hospital in Milan. He says, 'Turns out that it is harder than it looks?'

Researchers at San Raffaele



Hospital, Dr Daniele Canarutto (left) and Dr Francesca Ferrua (right).

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## Saying farewell to Jen



After working for over one-year for Immunodeficiency UK we are sad to say goodbye to Jen, our digital marketing and fundraising assistant. Jen is taking up a full-time, social media manager position at Age UK. Susan, Immunodeficiency UK's CEO, says 'Jen will be sorely missed. She has done a tremendous job for Immunodeficiency UK over the past year, coping with the reactivity needed during the COVID-19 pandemic, building our social media presence and membership, as well as supporting all our valued fundraisers. Jen was such a delight to work with and so supportive. I wish her every success in her new job'.

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## Call to take part in online research study

The healthcare market research recruiter, Medivoice Recruit, wants to learn more about the information resources available to people with primary and secondary

**Primary & Secondary Immunodeficiency**  
£140 for 90-minutes  
Online research study

Our client would like to speak to immunodeficient patients and family members of those taking immunoglobulins

This is not a clinical trial, simply a study to enable our client to learn more about the information resources available to patients and how they can be improved.

The study session will involve a 45-minute pre-task and a 45-minute interview for which you will receive £140 as a thank you for your time and opinions. No selling or promotion shall take place.

If you are interested in supporting this study, please e-mail: [susan.hughes@medivoicerecruit.com](mailto:susan.hughes@medivoicerecruit.com)

**medivoice**  
RECRUIT

immunodeficiency, and how they can be improved.

Medivoice Recruit's client, a pharmaceutical company, is aiming to produce market-leading patient resources to provide best-in-class support for immunodeficient patients taking immunoglobulins.

### **What is involved?**

Please note no selling or promotion will take place. The study is purely interested in your opinions and feedback to enable Medivoice to improve the pharmaceutical company's product. This research will be used to help the development of information sources to support patients of the future with immunodeficiencies.

This research will take the form of a 45-minute pre-task followed by a 45-minute online interview due to take place in early August. Participants will be paid £140 for their time and opinions and both patients and family members of patients can be included in this study.

If you go on to take part in this research, Immunodeficiency UK will receive a £20 donation.

Medivoice Recruit is particularly interested in learning:

- What information have patients/family members wanted about immunodeficiency?
- What information sources (e.g. websites, leaflets, books) they have used in the past to learn more about immunodeficiency?
- What information sources would have been most useful for you and other patients who have immunodeficiencies?

Anyone who may be interested in taking part in this study, would need to complete the questionnaire linked below:

<https://healthcarefieldwork.wufoo.com/forms/hsq004-immunoglobulins-patient-and-caregivers/>

#### How to get involved?

For further information, please contact Susan on 01223 855066 (option 1) or email: [susan.hughes@medivoicecruit.com](mailto:susan.hughes@medivoicecruit.com)

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## Our trustee Diane is doing an Olympic distance triathlon to raise vital funds



Immunodeficiency UK trustee Diane Hammond is taking on the challenge of a lifetime. On August 28th she'll be swimming 1.5km, cycling 40km and running 10km - to raise funds for our vital helpline that provides support and advice for those living with primary or secondary immunodeficiencies.

Diane has personal experience of living with an immunodeficiency, as herself and her daughter Rachel have both had their lives affected by them.

Diane says, "The pandemic has been a particularly difficult time for people who are especially vulnerable to Covid, many of whom, like Rachel, don't make a response to the vaccines and some are still shielding. Immunodeficiency UK has advocated for these patients, keeping them informed and supported in many ways, but especially through its helpline. Many find it to be a lifeline for advice, guidance and emotional support."

Diane can be sponsored [here](#).

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Take care and stay safe,  
Best Wishes,  
Susan  
The Immunodeficiency UK Team

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