IMMUNO DEFICIENCY UK

February Newsletter

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Welcome to the February Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member, we hope you are keeping safe and well and welcome to our February newsletter.

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

Spring and Autumn COVID-19 booster vaccines in 2023

On 25 January 2023, the JCVI (Joint Committee on Vaccination and Immunisation) advised the UK government that:

- people who are immunosuppressed (the term used by the JCVI) should have a booster vaccine in Spring 2023
- people who are immunosuppressed AND other people who are high risk, should have a booster vaccine in Autumn 2023

Following this advice, we expect the UK government and the NHS to roll out Spring and Autumn boosters in 2023. It's not possible to book one yet, but as soon as we can, we will update you with links for all four nations of the UK. On the 10th February the DHSC told us that they are ‘due to announce a further update on an upcoming Spring Campaign within the next month.’ Immunodeficiency UK has not yet received any information.

In its 2023 statement, the JCVI also advises that research should be considered to inform the optimal timing of booster vaccinations to protect against severe COVID-19 for groups who are at different levels of clinical risk.

Paxlovid rebound

Paxlovid is an anti-viral treatment for adults who are at risk of becoming seriously ill if they get COVID-19. It combines two antiviral drugs, nirmatrelvir and ritonavir and is a course of tablets taken over 5 days and should be started within 5 to 7 days of testing COVID-19 positive.

Paxlovid rebound describes a situation where people who are treated with Paxlovid recover and start testing negative, but then the COVID-19 infection

comes back – or rebounds – after a few days or weeks. This can mean either the symptoms of COVID-19 come back, or people test positive for COVID-19 again, or both. It is worth noting that COVID-19 rebound can also happen when people haven't received any COVID-19 treatment and, as yet, there is no published research to confirm that rebound rates are higher for people who take Paxlovid than for people who have no treatment.

Researchers don't fully understand why Paxlovid rebound happens, but they are looking at possible causes, such as a resurgence of the virus, a secondary infection, or how the body's immune system responds to the virus.

- News about Paxlovid rebound has made some people worried about taking Paxlovid but it is important to consider the potential benefits:
- There is good evidence that Paxlovid significantly lowers your risk of getting seriously ill or dying from COVID-19. This is still true if you experience rebound after taking it.
- You may not have any symptoms with Paxlovid rebound, and if you do get symptoms, they are likely to be mild. Very few cases of serious symptoms have been reported.

It is thought that rebound may be avoided in future by extending the course of tablets, but there is no published evidence to support this yet. The manufacturer of Paxlovid, Pfizer, is conducting a trial to investigate this. The results are expected in September 2023.

What should I do if I have Paxlovid rebound?

If you have taken Paxlovid to treat COVID-19 and think you may have Paxlovid rebound:

- Tell your hospital team or GP – whoever takes the lead on your providing care for your immunodeficiency.
- Report what's happened to the MHRA (Medicines & Healthcare products Regulatory Agency) via the Coronavirus Yellow Card scheme – this will help them monitor the extent of Paxlovid rebound amongst people who take it.
- Self-isolate for 5 days, as you may be infectious even if you have no symptoms.

NICE decides not to recommend Evusheld

On the 16th February the National Institute for Health and Care Excellence (NICE) published draft guidance NOT to recommend the drug Evusheld, (referred to as tix-cil by NICE), as a protective treatment for people for people who are high risk of the serious health complications and who do not have an adequate response to vaccination. The reason is the lack of evidence of its effectiveness against current COVID-19 variants. NICE's Evusheld decision will likely apply to the NHS across the UK. Visit: https://www.nice.org.uk/guidance/GID-TA11102/documents/129.

In the draft guidance NICE acknowledges the urgent unmet need for providing people with and the need for a rapid review process for future, similar therapies. It states:

'The committee agreed that there is an urgent unmet need for an effective prophylactic treatment for people who do not have an adequate response to vaccination. But the committee concluded that tix–cil should not be recommended because it is unlikely to be effective against most of the relevant variants in the appropriate time period for this evaluation (January 2023 and the 6 months after).'

'The committee recommended that the healthcare system develop a rapid appraisal process for neutralising monoclonal antibodies such as tix–cil so that effective products can be fast-tracked to eligible patients.'

Immunodeficiency UK says ‘The delay in government decision making and the subsequent lengthy NICE review process for Evusheld has resulted in a huge lost opportunity over the last year to make a real difference to the lives of people with immunodeficiency who continue to live with the threat of COVID. Our community has, and continues to be, all too aware of the urgent unmet need and rightly feels that a gross injustice has occurred. We welcome the news that NICE will develop a rapid review process for similar therapies as it infers acknowledgement that the current systems and processes are not fit for purpose to cope with the changing landscape of COVID variants and that speedy access to therapies is needed. We call on NICE to set up the rapid review procedure as soon as possible.’

Evusheld 2.0

Astra Zeneca has developed a new Evusheld therapy. It is known as AZD5156 and is long-acting antibody combination of cilgavimab, a component of the current Evusheld therapy, and a new long-acting monoclonal antibody (mAb), AZD3152.

AZD5156 has been developed to have broad neutralizing activity across different COVID-19 variants. Laboratory studies show that it retains neutralization against all known variants to date, including currently circulating Omicron subvariants that other COVID-19 mAbs have reduced or no neutralization activity against.

In a statement to Immunodeficiency UK, a spokesman from Astra Zeneca said ‘We are rapidly advancing our next generation long-acting antibody (AZD5156), now in late-stage trials, and aim to make it available as a new option for COVID-19 in the second half of 2023, subject to regulatory reviews and trial readouts.’ You can find more details below:

ClinicalTrials.gov
AZD5156 trial builds on established safety and efficacy of EVUSHELDTM

Clinical trials for Evusheld 2.0 – the SUPERNOVA study – healthy volunteers needed

The trials are known as SUPERNOVA and at present they want to recruit HEALTHY volunteers. You may know someone who may be able to take part in this important study. Eligibility criteria include:

- being healthy and between 18 and 55 years of age
- weighing between 45 and 110 kg
- not having tested positive for COVID-19 in the past 6 months
- not receiving a COVID-19 vaccine in the past 3 months

More information can be found here where you will find an information sheet and a pre-screening questionnaire.

Details on the full pilot involving an immunocompromised cohort will be released around April.

Consider joining your energy supplier's Priority Services Register

If you live in England, Scotland or Wales, you can contact your energy supplier to register as a vulnerable customer on their Priority Services Register.

What does being on the Priority Services Register do?
Many suppliers will give vulnerable customers advanced notice of planned power cuts and offer priority support during emergencies. Some may be able to provide cooking facilities, hot meals or charge points to households that rely on medical equipment.

Suppliers must take all reasonable steps to avoid disconnecting you during the winter months (1 October – 31 March). Suppliers that have signed up to Energy UK's Vulnerability Commitment cannot knowingly disconnect a vulnerable customer at any time of the year.

You can also join the register of your energy network operator. This is the company that provides the pipes and cables that bring energy from your supplier to your home.

What is a vulnerable customer?

Ofgem – the energy regulator – lists customers normally considered vulnerable. Households that are eligible include people who have reached the state pension age, are disabled, have a long-term medical condition and families with young children, and households that use medical equipment that requires a power supply.

How do I register?

Contact your energy supplier and ask them to put you on their Priority Services Register. You can also contact your local electricity network operator to ensure you are also on their register. Find out who that is.

Live in Northern Ireland?

Energy suppliers in Northern Ireland may operate their own schemes for older, disabled or chronically ill customers, such as the Medical Customer Care Register. Check with your supplier to find out more.

Will you support our work today and in the future?

We are doing all we can to help families affected by immunodeficiency, now and in the future and we'd really appreciate your help, if you can.

We receive no public funding and we rely on supporters like yourself to help us fund all the services we offer.

Can you spare £10 a month to help us be there for everyone whose lives are affected by immunodeficiency?

You can easily sign up online here to make an impact. Become a regular today and you'll enjoy:

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- Hassle-free automatic monthly donations from your bank account.
- The ability to change or cancel your donations at any time.

- The joy of knowing that you're helping us to support more people living with immunodeficiency.

Sign up

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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