

Welcome to the November Immunodeficiency UK newsletter!



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

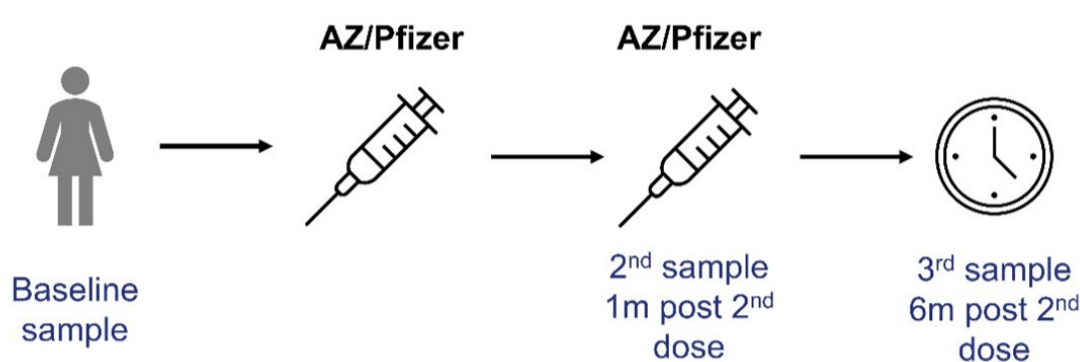
Read on for our monthly news round up and, as always, please don't hesitate to get in touch if you have any questions or comments.

New anti-viral drugs against Covid-19

COV-AD study interim results

During the pandemic, UK researchers have been gathering information about how COVID impacts patients with antibody deficiency through a national study called [COV-AD](#). Funded by UK Research and Innovation, COV-AD has now been running for just under a year and has to date recruited over 500 participants with primary or secondary antibody deficiency from 10 hospitals around England. The study is open to people attending immunology departments with very low levels of antibody.

The COV-AD study



The study team, run by Professor Alex Richter, University of Birmingham and Professor Siobhán Burns, University College London recently reported interim results at the bi-annual UK Primary Immunodeficiency Network meeting. These demonstrate that while 55% of participants made a detectable antibody response following two doses of COVID vaccination, the level of COVID antibodies generated was well below that seen in individuals with a healthy immune system. The COVAD study also examined T cells and found that just over half of participants do make a measurable T cell response to COVID vaccination. It remains unclear what protection a T-cell response or a low level of antibody provides from COVID infection and further work is ongoing to understand this.

The conclusion of the team is that many patients with antibody deficiency are likely to remain susceptible to COVID infection even after two doses of vaccination. It is clear though that both T-cell responses and low-level antibody responses were higher after the second dose of vaccination, supporting the importance of a 3rd primary dose and booster vaccinations for patients with antibody deficiency. More information about COVID 3rd dose and booster vaccinations can be found [here](#).

The COV-AD team has recently had approval to extend the study to capture additional information about antibody and T cell responses after a third dose of vaccination and will be contacting participants who have already been recruited with further details about this. The study, called [OCTAVE DUO](#), will remain open for new participants until the end of January 2022. Eligible participants will be contacted from their centre to invite them to take part. Thank you to everyone who is contributing to this study.

This article was written by Professor Alex Richter and Professor Siobhán Burns.

MHRA approves the anti-viral drug Molnupiravir

The drug Molnupiravir, developed by Merck Sharp and Dohme, has been shown in clinical trials to cut the risk of hospitalisation or death, due to Covid, by half (50%). [In the MHRA approval document](#), the recommendation is for the drug to be used "as soon as possible" following a positive Covid test and within five days of symptoms onset. The UK has agreed to purchase 480,000 courses with the first deliveries expected this month. Molnupiravir will be made available to vulnerable groups only through a national clinical study so that extra data on its effectiveness can be collected before the UK orders more. Immunodeficiency UK will keep you informed as and when we learn more about access for the immunodeficiency community.

[Molnupiravir: First pill to treat Covid gets approval in UK - BBC News](#)

Clinical trial results published on the anti-viral drug Paxlovid

In [clinical trials](#) the drug Paxlovid, developed by Pfizer, has been shown to cut the risk of hospitalisation or death by 89% in vulnerable adults. It is intended for use soon after symptoms develop in people at high risk of severe disease. The USA has apparently already ordered 'millions' of doses Paxlovid, but in the UK the drug has yet to go through the MHRA approval process. Access, when granted, is only likely to be available to specific sub-groups of patients through clinical trials in the UK.

[Covid: Pfizer says antiviral pill 89% effective in high-risk cases - BBC News](#)

Antibody testing after Covid-19 vaccination

Antibody tests to check your response to COVID-19 vaccination are not routinely available on the NHS, unless you are admitted into hospital with COVID-19, when an antibody test is taken to see if you are eligible for passive monoclonal antibody therapy, such as Ronapreve. There are companies that offer private antibody tests and it is a personal decision whether you choose to pay for private antibody testing. Some people have reported to us that having the knowledge of their antibody response after vaccination helps them deal with the risk of COVID psychologically. This [website article](#) gives you a few things to consider before deciding whether to pay for a test.

Presence of SARS-CoV-2 (Covid-19) antibodies in immunoglobulin products

Immunodeficiency UK now understands that low levels of anti-Covid-19 neutralising antibodies are now present in off the shelf immunoglobulin (IG) products. These low levels are highly unlikely to offer any protection against Covid-19 so, despite this welcomed news, we urge the community to continue to be careful and take the usual precautions.

New data on the presence of anti-Covid-19 neutralising antibodies in plasma donations in the USA was released in September 2021. You can read the paper [here](#). We will continue to keep you informed as we learn more. Please note Immunodeficiency UK does not have detailed information on the levels of anti-Covid-19 neutralising antibodies in the different IG products that are available to patients.

Access to Ronapreve for patients on immunoglobulin (IG) therapy

On the 4th of November 2021 the NHS published an updated version of the Interim Clinical Commissioning Policy: Casirivimab and imdevimab (Ronapreve) in the treatment of COVID-19 in hospitalised patients. This updated policy takes into account that low levels of antibodies to Covid-19 are now appearing at low levels in immunoglobulin (IG) replacement therapies (as above). Read more at [Immunodeficiency UK - Access to anti-Covid monoclonal antibody therapy Ronapreve](#).

Trustee vacancies at Immunodeficiency UK

We are looking for experienced members of the public to join our Board of Trustees who help steer our growth over the coming years and who will ensure adequate governance oversight of our much-needed services.

We are particularly keen to recruit people who have one or more of the following skills:

- Experience of living with or caring for a person with an immunodeficiency
- Expertise in Marketing, Communications, Fundraising or PR
- Charity finance, charity accounting (for treasurer role).

Board meetings are held online each month and take place on a Monday evening starting at 5pm for approximately one hour.

[Find out more](#)

Activated Phosphoinositide 3-kinase δ syndrome (APDS) - opportunities to make your voice heard.

Are you affected or care for someone with the condition Activated Phosphoinositide 3-kinase δ syndrome (APDS)?

Then there are two opportunities to make your voice heard.

APDS Patient Ambassador Program

The company Pharming Medical would like individuals who live with the condition Activated Phosphoinositide 3-kinase δ syndrome (APDS) or their carers to have a voice to educate others about their condition. The goal of our APDS patient ambassador program is to allow other people to understand what it is like to live with this rare and limiting condition. These ambassadors are not advocates for a specific therapy and indeed treatments will have very limited mention. Instead, they can share their experience of living with this rare disease, educating healthcare professionals, policy makers, the pharmaceutical industry, and the general public to develop a greater understanding of APDS.

Individuals should ideally be comfortable in speaking in public. Independent support will be given by specialist agencies who have supported individuals to tell their story in other rare disease areas. Initially, this will then be filmed to be used as an education resource. Potentially, when COVID criteria allow, there could be the potential for live presentations at patient or healthcare conferences. This program will be managed and run entirely outside of Pharming control, by an agency experienced in developing rare disease ambassador programs and as such any mention of any Pharming medication will be expressly forbidden.

APDS Patient Advisory board

The company Pharming Medical would also like to develop a patient advisory board for individuals who have Activated Phosphoinositide 3-kinase δ syndrome (APDS). These events are strictly non-promotional events to allow Pharming to understand the patient experience in diagnosis, access to therapy and impact of the condition on working, school, or home life. These insights are highly beneficial and allow deeper understanding of the condition, which we ultimately hope will benefit patients, carers and their wider families.

Unfortunately, compliance legislation means that Pharming Medical cannot pay individuals to attend these meetings, which would likely be on-line due to ongoing COVID concerns.

Should you be interested in either of these programmes, please initially get in touch with Immunodeficiency UK at hello@immunodeficiencyuk.org to highlight your interest.

Immunodeficiency UK's Festive Photography Competition



This winter, we'd love to share your most merry and bright photos with our Festive Photography Competition!

The theme this year is '**Merry and Bright**'. This could be anything that inspires you or lifts your spirits in the depths of mid-winter.

To enter, post your photo on facebook or Instagram and tag us @ImmunodeficiencyUK. Alternatively, you can email your picture to Jen at jen.rush@immunodeficiencyuk.org stating that you give permission for us to share your name and photo on our social media channels.

We'll be choosing three winners for the categories **Cheerful**, **Heartwarming** and **Festive**.

The competition is just for fun, but we're sure Santa's helpers will have a little surprise for our category winners!

Entries close on December 10th, when all photos will be added to a Facebook album for the whole community to enjoy.

Please help support Immunodeficiency UK while you shop online for Christmas

Did you know you can donate to Immunodeficiency UK at **no cost to you** while you shop? Simply register with one of the following platforms and businesses will donate a percentage of your spend on your behalf.

The pennies soon add up to pounds for Immunodeficiency UK, so please do take a moment to register for free before you start your festive shopping!



Register for free and over 4,000 shops and sites will donate to us at no cost to you every time you use easyfundraising to shop with them.

Donation amounts vary depending on the company you're shopping with and there are often additional offers, so it's worth signing up to their mailing list too!

Register for easyfundraising



You shop. Amazon gives.

Select Immunodeficiency UK as your chosen Amazon Smile charity and when you shop as usual, the company donates 0.5% of the price of eligible purchases to us.

Register for Amazon Smile

Thank you for supporting Immunodeficiency UK



Thank you to everyone who has recently donated to Immunodeficiency UK.

We would like to say a special thank you to those who have donated and raised funds in memory of a loved one. We are honoured that you choose to support Immunodeficiency UK in this way.

Your generosity enables us to continue to support families and individuals affected by immunodeficiency. Thank you

In memoriam gifts

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

Supported by an educational grant
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