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Welcome to the October 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.

Update on the immunoglobulin supply situation

Recent communications from the NHS (August 2021) have indicated that there will be up to a 14% decrease in supply of IG for at least the next six months. Some immunoglobulin products are impacted more than others, and this means that you may have to be switched to other IG products, which are in more abundant supply, so that you can continue receiving your treatment.

Clinicians, pharmacists and Immunoglobulin Assessment Panels have been provided with guidance, endorsed by the body representing medical professionals, the UK Primary Immunodeficiency Network (UKPIN), on how to manage the short fall.

Switching, where needed, will be made following your consent and in discussion with your clinical team, who will support you throughout the process. It is our understanding that you will be given an NHS patient information leaflet describing why this is happening and what this means for you. Immunodeficiency UK unfortunately cannot signpost you to the NHS leaflet yet, but [our own leaflet on switching](#) may be helpful to you.

Read more at [Immunodeficiency UK - Immunoglobulin availability - impact of COVID](#)

Has your immunoglobulin treatment been affected adversely by the immunoglobulin shortage situation? If so, we would like to hear from you.

Please contact us at: hello@immunodeficiencyuk.org

Access to medicines and update on monoclonal antibodies for the treatment of Covid-19

The approval of a new medicine and the steps that follow to ensure it is successfully rolled out to patients are complex and lengthy. Fortunately, in the case of public health emergencies, such as the COVID-19 pandemic, health authorities can accelerate some of their processes to facilitate quicker access to new treatments for patients. This [article](#) helps explain what processes are involved.

In an accompanying [article](#) we bring you up to date on monoclonal treatment (Mab) options for patients with immunodeficiencies and compare their approval status in the UK, Europe and the USA. As we know anti-Covid Mab therapies offer promising alternatives for members of our community who have limited or no response to the COVID-19 vaccines. Immunodeficiency UK will continue to lobby for timely access to these treatments.

Want to ask a question about vaccinations?

Please consider registering to join the Zoe webinar: How are COVID vaccines working in the immunocompromised?

It takes place on Thursday, October the 28th at 3 pm: 'Over half a million people in the UK have a compromised or suppressed immune system, and rightly want to know more about how COVID vaccines are working for them. Our panel of experts will be discussing how vaccines are working in those with a compromised immune system, what alternatives may be considered, risk of COVID infection and how long antibodies are lasting, if at all.' [Click here](#) to register.

Immunodeficiency UK has no control of the content of the webinar, but we understand that once you register you can submit your questions and the most popular are addressed, so we encourage you do so to get the voice of people with primary and secondary immunodeficiency heard.

Get your Covid and flu jab



The flu and the COVID-19 vaccines can be given at the same time. It is important that people take up the offer of both vaccines when they receive it, so people are encouraged to get both vaccinations as soon as possible rather than waiting for the possibility of getting them together.

There are very few places, other than schools, doing both together. COVID vaccination tends to be vaccination centres whilst flu vaccinations is happening through mainly pharmacies or GPs.

Treatments for Covid-19

AstraZeneca antibody injection able to prevent and treat coronavirus, latest study shows

AstraZeneca has produced a COVID-19 cocktail combining two monoclonal antibodies, AZD7442, with potential to treat infected patients and as a preventative treatment which will confer protection for 6-12 months. The treatment can be injected or administered intravenously. The results of the

[Phase III trials](#) are promising and achieved a statistically significant reduction in severe COVID-19 or death compared to placebo in non-hospitalised patients with mild-to-moderate symptomatic COVID-19. AZD7442 reduced the risk of developing severe COVID-19 or death (from any cause) by 67% compared to placebo.

AZD7442 has already been submitted to the US Food and Drug Administration for emergency use as a preventative treatment. We understand that the UK government has an in-principle agreement with AstraZeneca which it says secures access to a million doses of AZD7442 if it is successful in Phase 3 trials.

Immunodeficiency UK says: 'This trial proves conclusively that monoclonal antibody (Mab) treatments protect people who have not responded fully to Covid vaccinations. This treatment, along with the Roche Mab product Ronapreve, must be made available to immunodeficiency patients in the UK so that they no longer have to live in fear of Covid and can rejoin society.'

Covid antiviral pill can halve risk of hospitalisation

The Merck drug molnupiravir cuts the risk of hospitalisation or death by about half, interim clinical trial results suggest. If authorised by regulators, molnupiravir would be the first oral antiviral medication for Covid-19. Read more [here](#).

New IPOPI App



IPOPI have launched a new health agenda application for patients with primary immunodeficiency, called 4ID.

It has been developed by IPOPI to support patients in managing their conditions. 4ID is designed to help patients get organised and keep track of what's important to them, their families and their doctors in a simple way. You can try the new app here: <https://4id.ipopi.org>

Well done Chelsea!



A big well done and thank you to Chelsea, who took part in this year's Great South Run.

Chelsea raised over £1,000 for Immunodeficiency UK!

Thank you, Chelsea!

New art project explores the reopening of the world



WAVES
Michael Wight's job exhibition

Michael has XLA and is an artist. He has just released a new selection of work called Waves. He says:

'Welcome to Waves, my fifth project. This project is a big piece of exploration for me, and in many ways, it is the main theme here. Exploration. When shielding finally ended for me last year, and the world opened, I knew I had to savour it.

This very action, a need for exploration and to be outside in elements and conditions deprived from me, Waves became my next project. I had plans to craft a different, more medical based project, but I found myself in nature more, outdoors all the time and worshipping the freedoms that came with simply living. Waves reflects that time, and is also a commentary on relationships, the importance I've felt as a person over the last year and how nature and our lives can be very linked.'

Have a look at Michael's work at www.michaelwightart.co.uk

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](#)

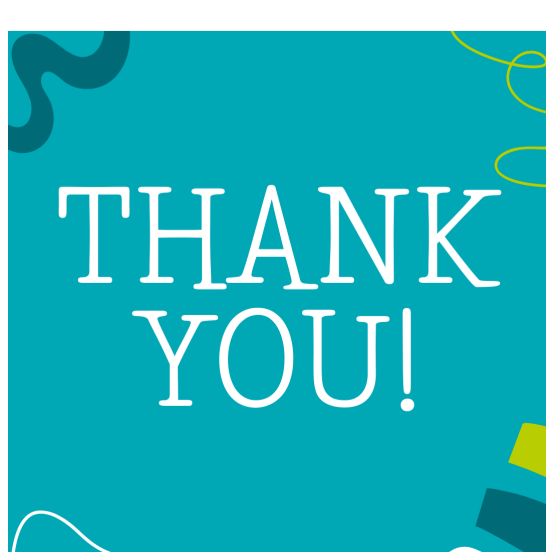


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Thank you to everyone who has recently raised funds and donated to Immunodeficiency UK.

Your generosity enables us to continue to support families and individuals affected by immunodeficiency. We are extremely grateful for all your support.

If you would like to make a donation to Immunodeficiency UK, please visit the

donation page of our website.

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

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