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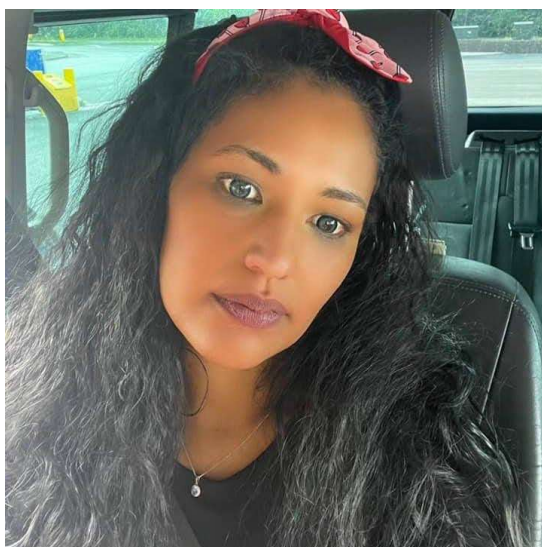
Welcome to the August Immunodeficiency UK newsletter!



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.

Saying hello to Fay, our new digital communications, marketing and fundraising assistant



Fay has seven years' experience in marketing and communications for charities and the public sector and is currently completing a degree in marketing. She is passionate about increasing fundraised income to allow charities to provide more expansive services to the people they support.

Fay has experience across a wide variety of digital marketing and communications activities and has previously worked at the youth cancer charity

Teenage Cancer Trust and older person's charity MHA.

She said 'I am excited to be working for Immunodeficiency UK and I look forward to engaging and connecting with supporters and the community. I hope, in my ten hours per week, to use my fundraising skills to ensure that even more people who are affected by immunodeficiency get the help and support that they need.'

We need your help – NICE assessment of treatments for COVID-19



Immunodeficiency UK has been asked by the National Institute for Health and Care Excellence (NICE) to take part in a multiple technology appraisal (MTA) on therapeutics for people with COVID-19. NICE has given us a very short timeline to respond to the consultation.

If you are affected by a primary or secondary immunodeficiency, or a care-giver of someone affected and you haven't already taken part please give us your experience and views on living with and views on living with COVID-19 and access to COVID-19 treatments through this survey: <https://www.surveymonkey.co.uk/r/67ML38L>.

Thank you if you have already taken part!

Latest news about Evusheld

Evusheld was approved by the UK regulator, the MHRA, in March. Now, five months later, the Department of Health has rejected its use for the foreseeable future.

The announcement made by government spokesperson on the 13th

August says:

“Following a robust review of the available data, our clinical experts advise there is currently insufficient data on the duration of protection offered by Evusheld in relation to the Omicron variant and the government will not be procuring any

doses at this time. We are determined to support the most vulnerable as we live with Covid and immunocompromised patients are a priority for other treatments, access to free tests and vaccination. We continue to explore the market for promising treatments that could prevent infection, to add to the antibody and antiviral treatments that are already offered on the NHS. We remain in close touch with all relevant parties.”

A spokesperson from Astra Zeneca said: “Astra Zeneca have not been asked to safeguard any supply for the UK immunocompromised groups with Evusheld for the Autumn/Winter. We have not been asked to consider guaranteeing any supply until Summer 2023 at the earliest”.

The news has come following months of concerted lobbying calling for access to Evusheld from individual patients, charities, the Evusheld Campaign Group, numerous MPs and leading clinicians – see below.

NICE are currently consulting around the effectiveness of Evusheld. This process usually takes quite a few months, meaning a decision is unlikely to be reached until sometime in early 2023.

Clinicians sign a clinical consensus statement calling for access to Evusheld

NATIONAL CLINICAL EXPERT CONSENSUS STATEMENT

Coronavirus monoclonal antibodies as a prophylactic therapy against COVID-19 for immunocompromised groups

One hundred and twenty clinicians covering 17 different clinical specialities, including many consultant immunologists, have produced clinical-based consensus recommendations for the use of Evusheld as a prophylactic antibody therapy for people who are immunocompromised who have not responded to vaccination. It states that a protective antibody therapy program should be delivered as soon as possible and underlines that there is sufficient evidence that the COVID-19 preventative Evusheld would have clinical benefit and how the rollout would work.

Immunodeficiency UK joins 18 charities calling for access to Evusheld



We know that for a significant proportion of people affected by an immunodeficiency, the first lockdown in 2020 never ended, which is why over 18 charities including ourselves, [signed an open letter](#) to Steve Barclay MP on the 28th July, urging the Government to buy Evusheld to protect the people they represent who remain vulnerable to Covid-19.

Margaret, a patient with CVID, gives us her reaction to the Government's decision:

'How devastating it is for us and you and all the charities who have fought for us in the last couple of years. Thank you for everything you have done. All the efforts with the media, letters written and publicity via our FB page, and here we are back at square one! I kept thinking maybe this Autumn and if not then maybe early next year? I think this weekend has been the toughest of all.

The APPG and medical support have all been swept away. I have kept myself cocooned for 30 months waiting for salvation that clearly isn't coming! So now that Evusheld, actually does still seem to work against new variants, they change the goalpost and say they are not sure that the protection will last long! It is particularly hard knowing so many other countries have given Evusheld to people like me. It makes me question the decision making and what worth I have to society in a health system that promises to eliminate health inequality.

So, I suppose I will have to reassess my risk levels. I haven't been in a supermarket, a friend's house, a hotel, a theatre, a cinema, a museum, a taxi, a train, a bus or shared a car with anyone other than my family. I have only met in gardens but with winter coming again I'm not sure that is something I want to do

for the third time!

An article in the Daily Mail, earlier this year, wrongly said that Evusheld was available privately. The newspaper was inundated with patients desperate to pay for it themselves, as the government don't think we are worth the investment. I would risk flying abroad to get it too. I feel abandoned, duped, and angry.'

Susan, Immunodeficiency UK's CEO, says 'This is a cruel blow and leaves many people in our community in limbo. The UK lags behind 32 other countries in providing access to Evusheld and there is now compelling real-life data available showing that Evusheld reduces the chance of dying from COVID-19 for immunocompromised groups. The decision-making process has been extremely slow and frustrating, with little transparency. The pandemic is not over, and it is yet again going to be a difficult winter, full of anxiety, for many people affected by immunodeficiency. We call on the Government to provide their rationale for delaying access to Evusheld and to review the decision.'

JCVI publishes advice on COVID-19 vaccines for autumn booster programme



The Joint Committee on Vaccination and Immunisation (JCVI) has published its advice on which COVID-19 vaccines should be used in this year's autumn booster programme. It includes the new Moderna vaccine.

It is worth noting that there is no guarantee as to which vaccine you will be offered. The booster programmes are due to start in September and you can find out full information about the eligible groups here.

Autumn booster programmes:

England - 'NHS England will confirm details on how and when eligible people can access the autumn booster vaccine in due course'.

Wales - 'Please wait to be invited, your health board will contact you when it's your turn. Please do not contact your GP to ask about appointments'.

Scotland - 'Letters will be sent out to the first eligible groups next month with appointments beginning in September.'

Northern Ireland - 'details to be announced'.

About Quality in Primary Immunodeficiency Services (QPIDS)



Quality in Primary
Immunodeficiency Services

The QPIDS accreditation unit work closely with clinical services across the UK, Scotland and Ireland to support improvement in immunodeficiency services and ultimately to enable better quality of care for patients.

QPIDS now has 39 registered services, 22 are accredited with 17 working towards their accreditation. Accredited services must prove they are adhering to the QPIDS standards by submitting evidence for their annual reviews, in their fifth year they are required to submit for reaccreditation.

If a service is accredited, it means they have met a rigorous set of standards, which have been agreed nationally with clinicians, managers and patients. To meet the standards, services must have ensured patients are involved in decision-making about their care, monitoring of clinical performance and carrying out audits to benchmark and improve, providing training and support to the staff working in the service and learning from incidents to prevent harm.

QPIDS have created a video for patients explaining in more detail what the accreditation pathway entails. You can view the video on their [website](#). If you have any further questions about accreditation and what it means please contact the QPIDS team at askqpids@rcp.ac.uk.

If your centre is not yet accredited, Immunodeficiency UK suggests you ask your centre how far along they are in the process and when they hope to be fully accredited.

FUNDRAISING IDEAS



The work we do here is only possible thanks to your support. Our supporters regularly fundraise on our behalf and we have much more work to do to ensure that everyone with a primary or secondary immunodeficiency feels fully supported.

There are so many ways that you can help us raise funds to support our work and below you'll find 3 fun ways to fundraise on our behalf:

Book Sale

Ask your child's school, your family members and your friends to donate books that they no longer have a use for. These can then be sold to raise funds for our work.

Garage Sale

Why not gather up sellable items from family and friends and host your own garage sale. This can be a good way to raise funds while also clearing your house of things you no longer need.

Charity Auction

Get in touch with local businesses and ask them to to make donations for a charity auction; they can donate their own goods and services to be auctioned off. Secure a venue, sell tickets and get refreshments in place. It is the perfect event to run with a group of friends. It is a lot of work but can be a great way to raise a lot of money.

If you require any support or have any questions regarding fundraising for Immunodeficiency UK, please get in touch with Fay via email at

fay.fagon@immunodeficiencyuk.org

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

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