



August
Newsletter

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Welcome to the August Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member, we hope you are having a good summer so far.

We have a lot to update you about in this month's newsletter.

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

Your Voice Matters – PID/ SID Patient Experience Survey

Survey deadline extended!

IMMUNO DEFICIENCY UK Supporting families affected by primary and secondary immunodeficiency

Patient Experience Survey Your Voice Matters

Do you want to help us improve our understanding of the impact of primary immunodeficiency and secondary immunodeficiency on a patient's quality of life?

If you, your child, parent or family member have been diagnosed with a primary or secondary immunodeficiency you are invited to complete a market research survey about **your experience** of living with your condition and the care you receive.

There is no obligation for you to take part and it will not affect your care in any way if you do or do not decide to complete the survey.

The survey, which is available to UK respondents over the age of 16 only, will initially be available until 7 August 2023 but may be extended depending on patient recruitment. As a thank you for your participation, you will receive a £15 Amazon voucher.

For more information on how to take part please scan the QR code below or enter the following link into your browser:
idusurvey2023.co.uk

If you know someone in the UK with a diagnosed primary immunodeficiency (PID) or secondary immunodeficiency (SID), please share this invitation to participate in our patient survey.
Thank you

This survey has been conducted by an independent healthcare communications consultancy, (Interaction Marketing & PR) based in the UK, complying with UK Data Protection law and with the British Healthcare Business Intelligence Association's Legal & Ethical Guidelines, and has been developed in collaboration between Immunodeficiency UK and Takeda UK Ltd, and funded by Takeda UK Ltd. Registered Charity number 1193166 <http://www.immunodeficiencyuk.org>. All applicable laws are abided by regarding the protection of your responses and personal data. July 2023 / C-ANPROM/GB/IG/0258

There is still time to take part in our PID/ SID patient experience survey if you haven't done so already. We are extending the closing date to August 31st.

If you would still like to get involved and share your experience complete the survey at: www.iduksurvey2023.co.uk.

As a reminder, the online market research survey is for individuals or family members living with primary or secondary immunodeficiency in the UK to help us learn more about your experience of living with your condition and the care you receive.

Respondents must be in the UK and over 16 only (the survey may be completed on behalf of someone who is 16 or under). It should take between 20 and 30 minutes of your time.

As a thank you for completing the questionnaire, respondents will have the option of receiving a £15 Amazon voucher. Vouchers will be distributed once the survey has closed and the relevant quality checks have been carried out.

Should you have any questions regarding the survey or vouchers please reach out to admin@iduksurvey2023.co.uk

This survey is being conducted by an independent healthcare communications consultancy, (Interaction Marketing & PR) and has been developed in collaboration between Immunodeficiency UK and Takeda UK Ltd., and funded by Takeda UK Ltd.

Listeria risk from ready-to-eat smoked fish



The Food Standards Agency (FSA) and Food Standards Scotland (FSS) have contacted Immunodeficiency UK to tell us about their updated guidance on the

risk posed by Listeria infection from ready-to-eat smoked fish to people with weakened immune systems. Please read the latest information at [Immunodeficiency UK - Listeria monocytogenes risk and ready-to-eat smoked fish](#).

Autumn's COVID-19 vaccination roll-out



The Joint Committee on Vaccination and Immunisation (JCVI) has [announced its advice regarding persons who will be eligible for a COVID-19 booster vaccine in autumn 2023](#).

Household contacts of people who have weakened immune systems (referred to as 'immunosuppressed people') are now eligible for COVID-19 vaccinations.

The JCVI has advised that the autumn programme should aim to complete vaccinations by early December 2023.

Visit [Covid autumn booster vaccine 2023: Everything you need to know - Department of Health and Social Care Media Centre \(blog.gov.uk\)](#) for the DHSC Q&A factsheet.

Access to vaccines



In England, NHS England will confirm details on how and when eligible people can access the autumn booster vaccine 'soon'.

In Scotland, NHS Scotland will contact people with details of their appointment, or may contact them prompting them to book. Details will be posted at [The coronavirus \(COVID-19\) vaccine | NHS inform](#)

In Wales, all eligible individuals will receive an appointment invitation from their local health board. [COVID-19 vaccination programme | GOV.WALES](#)

In Northern Ireland, the Public Health Agency will confirm details on how and when eligible people can access the autumn booster vaccine in due course. Details will be posted at [Get a COVID-19 vaccination in Northern Ireland | nidirect](#)

Vaccination advocacy activities



In July, Immunodeficiency UK joined a coalition of seven other charities to write to Parliamentary Under Secretary of State at the Department of Health and Social Care to highlight the need for improvement of future vaccine rollouts given the experience of our communities during the spring booster campaign.

The letter asks for increased transparency of the data sources used to select eligible groups; the need to address vaccine refusal at vaccination sites, for protective measures at vaccination sites, and for renewed messaging to deal with booster fatigue and health disparities so that take up can be maximised. You can read the letter [here](#).

Change in how to access lateral flow tests in Northern Ireland



Immunodeficiency UK has just heard from Northern Ireland's Department of Health that from the 31st July free lateral flow tests (LFTs) will no longer be available to order online or via the 119 telephone line. Those eligible should collect free LFTs via the 'Pharmacy Collect' service.

More information can be found at:

Benefits - light touch PIP forms introduced by the DWP



The Department of Work and Pensions (DWP) have created a light touch review form for claimants of Personal Independence Payment (PIP) who have reached pension age or who have an ongoing PIP award. The AR2 form is being issued from August 2023. Read more at [PIP AR2 light touch review form, details and sample copy \(benefitsandwork.co.uk\)](#).

Need guidance in making a claim for benefits? Then Immunodeficiency UK, as a member of Benefits and Work, can provide you with guides to help with your application process. Get in touch with us at hello@immunodeficiencyuk.org and tell us which benefit you are claiming for.

Opportunities to take part in research

Stravinsky study

Stravinsky



STRAVINSKY stands for 'Stratification of Clinically Vulnerable People for COVID-19 Risk Using Antibody Testing.' This study aims to establish if antibody testing can identify who remains at greatest risk of severe COVID-19 infection after vaccinations.

To take part you can self-refer by contacting stravinsky@contacts.bham.ac.uk with your name, address, condition and specialist centre. Visit [STRAVINSKY | British Society for Immunology](#) for more information and you can follow the study on <https://twitter.com/STRAVINSKYstudy>.

PANORAMIC trial

Sign up for **PANORAMIC** and help us find new antiviral medicines for treating **COVID-19** in the community.

You can take part without leaving your home.



☑ Tested positive for COVID-19 with symptoms starting in the last five days?

☑ Aged 50 or over? Or 18 or over with an underlying health condition?

Contact the trial team: **08081 560017**
www.panoramictrial.org



PANORAMIC_PortraitPoster_V1.0_23Apr2023_Postor2 IRAS Project ID: 1004274 Ethics Ref: 21/SC/0393

Immunodeficiency UK has been contacted by Clinical Trials Unit at the University of Oxford's Nuffield Department of Primary Care Health Sciences to ask us to highlight the PANORAMIC trial - a UK-wide clinical study which aims to evaluate the efficacy of novel antiviral treatments for COVID-19 in the community.

PANORAMIC is open to everyone with ongoing symptoms of COVID-19 and a positive PCR or Lateral Flow test, regardless of vaccination status.

You can participate in your own home from anywhere in the UK. No face-to-face visits are required.

The eligibility requirements are:

- You are currently experiencing COVID-19 symptoms beginning in the last 5 days.
- AND: You have had a positive PCR or Lateral Flow test for COVID-19

- AND: You are aged 50 or over, OR aged 18 or over with a [LISTED](#) pre-existing condition*. *This study is open to all people affected by primary and secondary immunodeficiency.

Visit [Participant Information — PANORAMIC \(panoramictrial.org\)](#) for more information.

The PANORAMIC trial allows for a wider group of people to gain access to anti-viral medications via a clinical trial but please note if you are in the highest risk group for COVID-19 you should still seek access to COVID-19 medicines directly via the [NHS](#).

NICE appraisal of Evusheld2 (AZD3152)



The National Institute for Health and Care Excellence (NICE) have informed Immunodeficiency UK that, following information received from Astra Zeneca, the appraisal of Evusheld2 (AZD3152; see the SUPERNOVA article above) has been rescheduled. NICE now expect that the drug appraisal process to start in early 2024. This is because the Medicines and Healthcare Products Regulatory Agency (MHRA) need to approve the drug's safety before a NICE assessment can start.

A coalition of charities, including Immunodeficiency UK, and patient organisations has written to the Chief Medical Officer at NICE to raise concerns about the lack of progress regarding the proposed speedier assessment route for new COVID-19 protective and treatment drugs. You can read the letter [here](#).

UK Plasma Fractionator

Immunodeficiency UK is still waiting for news about the name of the company contracted to act as the fractionator of UK plasma.

This will be a landmark step to having immunoglobulin products made from UK derived plasma making the UK less reliant on external supplies. We will keep you posted.

Recent news - in July the MHRA approved the use of albumin sourced from UK plasma. This now makes plasma fractionation a much more cost-effective process. Albumin is used to replace blood volume loss resulting from trauma such as severe burns, or an injury that causes blood loss, as well as for other medical conditions. You can find out more about plasma at [What is plasma used for? - NHS Blood Donation](#).

Can you provide regular support?



Support our
work

By making a
regular
donation

Please consider taking your support to the next level by becoming a regular giver. Your regular contributions will provide us with a stable foundation to plan for the future, expand our outreach, and make an even greater impact in the lives of those who rely on our services.

Regular giving is a simple and effective way to ensure that our vital work can continue. By committing to a monthly donation, from as little as £5/month, you'll be joining a community of committed supporters who are making a lasting difference. Together, we can bring hope and relief to those facing the challenges of immunodeficiency.

Visit [our website](#) to become a valued regular giver. Your support will help us create a brighter future for lives affected by immunodeficiency.

Thank you Katy



In 2017, Katy lost her uncle to Common Variable Immune Deficiency, better known as CVID, a disorder that he struggled with for most of his life. As many of our members know, CVID increases the risk of infections due to the body not being able to produce enough antibodies, and is managed via immunoglobulin infusions, but unfortunately there is no cure.

Katy's dad also suffers from CVID and for all of her life she has watched him have to inject himself with medication and struggle constantly with different infections, each one leaving him a little weaker.

So, Katy decided that she would take part in a skydive to raise money for Immunodeficiency UK. The skydive took place in July and we couldn't be more grateful. Katy raised a whopping £2,295 and we would like to say a huge THANK YOU to her for supporting our work.

Best Wishes,

Susan and Fay
The Immunodeficiency UK Team

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from Biotest (UK) Ltd



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