



October
Newsletter

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Welcome to the October Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

We hope the month is treating you well 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.

Volunteers still needed for research study

Participants needed for research on Primary and Secondary Antibody Deficiency (PAD/SAD)!

What is the research about?

The aim of this study is to explore patients' experiences of living with a PAD/SAD and how this impacts their quality of life. This research is being completed as part of a doctoral degree in Health Psychology.

Who can take part?

Any UK adult aged 18+ with a Primary or Secondary Antibody deficiency diagnosis. You must also be able to speak the English language.

Why is this research being conducted?

The findings from this study will help researchers understand patients' experiences of living with PAD/SAD. Interviews will be analysed and used to develop a questionnaire which will measure quality of life in adults aged 18+ with PAD/SAD.

What does the study involve?

You will be asked to complete one interview online via phone or videocall. The interview will explore how PAD/SAD impacts your quality of life and will take approximately 45 minutes to complete (this will depend on how much information you would like to share).

How can I take part?

If you would like to part, or have any further questions about this study, please contact Danielle Musson on d.musson7777@student.leedsbeckett.ac.uk

Or sign up using the below link: https://leedsbeckettpsych.eu.qualtrics.com/ife/form/SV_aXnCxt6RTKfRZ4



LEEDS
BECKETT
UNIVERSITY

Researchers at Leeds Beckett University are inviting people aged 18+ diagnosed with a Primary or Secondary Antibody Deficiency (PAD/SAD) to participate in a remote interview. The interview, which will take approximately 45 minutes will explore your experience of living with PAD/SAD and how the condition impacts your quality of life. Researchers are looking to speak to anyone with an antibody deficiency. The researchers would particularly welcome speaking with patients who have a secondary antibody deficiency or been diagnosed with PAD or SAD but have not started Immunoglobulin replacement therapy.

The PhD study is being conducted as part of a wider project which aims to develop a questionnaire which will measure quality of life in adults with PAD and SAD. This is an important project which needs your input so please consider taking part. If you would like further information, please contact Danielle Musson on d.musson7777@student.leedsbeckett.ac.uk.

You can also sign up to the study using the following link:

https://leedsbeckettpsych.eu.qualtrics.com/jfe/form/SV_aXnCxt6RTKfDRZ4

The NHS app



The graphic features a hand holding a smartphone displaying the NHS App interface. To the right, a yellow folder with a stethoscope is shown. The text 'See your GP health record on the NHS App' is prominently displayed in blue. Below this, three bullet points describe the app's features: 'you can see all new entries', 'includes consultation notes, medicines and immunisations', and 'need help? Get support in the app or visit nhs.uk/helpmeapp'. At the bottom, there is an 'NHS App' logo, a QR code, and icons for the App Store and Google Play.

The NHS is giving people access to their GP health record on the NHS App, NHS website and other GP online services. This means people will be able to easily access information including consultation notes, test results and letters. Access to your GP record can be made through the free NHS App or online account.

If you haven't downloaded the NHS App to your smartphone or tablet, you can find out how to online at <https://nhs.uk/helpmeapp>.

If you have the NHS App or an online account and you cannot see your record you can ask your practice to make it available to you.

Once you have access, you will be able to see information from any consultations going forward.

The STRAVINSKY study – new resources available

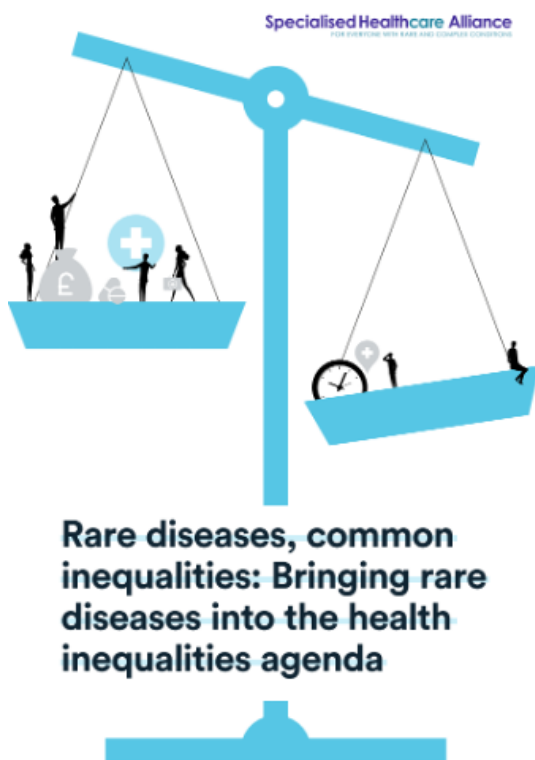
Stravinsky



New resources for the study 'Stratification of Clinically Vulnerable People for COVID-19 Risk Using Antibody Testing' (STRAVINSKY) have been posted for people who are considering taking part in the STRAVINSKY study and those who are already signed up. STRAVINSKY aims to increase the understanding of who is most clinically vulnerable to COVID-19 infection and identify individuals or disease groups at highest risk. The resources discuss what is involved if you decide to volunteer along with some videos to provide more information.

Find out more about the research and access the new materials at ['Extra information on taking part' in STRAVINSKY | British Society for Immunology.](#)

Report on inequalities in healthcare for people with rare diseases



The Specialised Healthcare Alliance (SHCA) has published the report 'Rare diseases, common inequalities: bringing rare diseases into the health inequalities agenda'.

The report contains 8 key recommendations to support equitable access to services for people with rare diseases, in comparison to those with more common conditions, ensuring that everyone has the same opportunity to live as healthily as possible.

The recommendations cover the lack of knowledge, understanding and awareness among healthcare professionals; poorly coordinated care; the scarcity of specialised centres/services across the UK; the lack of funding for rare disease research; accessing clinical trials; the delays in medicines

approval; need for better mental health support and the financial impact of a rare disease.

Changes in access to free lateral flow tests in England



From 6 November, arrangements in England will be in place to pick up free lateral flow tests from community pharmacy for patients who are eligible for COVID-19 treatments. This will replace the current process of ordering tests online and via 119. We understand the NHS UK website will be updated to reflect this change soon and NHS England have promised us further information on how this will work soon. We will keep you posted.

In Scotland: you can use this link to order lateral flow tests - [GOV.UK](https://www.gov.uk) (www.gov.uk). When you enter a Scottish postcode, the online order form will say 'Most people in Scotland can no longer get free rapid lateral flow tests' Click 'Continue' if you are eligible and you will be able to order.

In Northern Ireland: those eligible should collect free LFTs via the 'Pharmacy Collect' service. More information can [be found at Coronavirus \(COVID-19\): testing and stay at home advice | nidirect](#).

In Wales: information on accessing LFTs in Wales can be found at [Get tested for coronavirus \(COVID-19\) | GOV.WALES](#)

Cases of Flu are on the increase and antivirals for the prophylaxis and treatment of flu can now be prescribed for clinical at-risk groups or in anyone at risk of severe illness or complications from influenza.

It can be difficult to distinguish between the symptoms of COVID-19 and flu so for people who have a significant immune deficiency it may be worth considering buying a lateral flow test for flu (cost between £1 - £2).

People with a positive Flu A/B test can access antivirals (oseltamivir or zanamivir) via their GP or their specialist centre. People with PID/SID who have had a known household contact but are currently asymptomatic may also be eligible.

For people with existing co-morbidities such as diabetes, COPD, bronchiectasis and heart disease accessing treatment is recommended and must start ideally within 48 hours of symptoms to be useful.

Recent frequently asked questions from our helpline

Q. Can I be vaccinated if I have had a severe allergy?

A. There are very few individuals who cannot receive the COVID-19 vaccines approved in the UK. Where there is doubt, rather than withholding vaccination, appropriate advice should be sought from the relevant specialist e.g. an allergist or immunologist, or from the local immunisation or health protection team.

Q. Can I have immunoglobulin therapy on the same day as COVID-19 and flu vaccinations?

A. In these circumstances it would be difficult to know which of the treatments has given a reaction if these are given in the same day. Speak to your health team for advice that covers your specific medical circumstances.

Thank You Bourne2Sing



Huge thanks to members of Bourne 2 Sing, an Eastbourne-based choir, who recently raised funds to support our work by hosting a concert with proceeds going to Immunodeficiency UK. Around 80 people attended on the night and were treated to a spellbinding performance from the singers.

The choir's effort and hard work paid off as they raised over £800 for Immunodeficiency UK.

The work we do is only possible thanks to the generosity of supporters like Bourne 2 Sing and we are so incredibly fortunate to have such great support.

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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