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IMMUNO DEFICIENCY UK

April Newsletter

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Welcome to the April Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member, we hope you are keeping safe and well and welcome to our April newsletter. We hope you will find it informative.

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

Get your COVID-19 Spring booster

Starting this month, the Spring Covid-19 vaccine booster is being offered to adults aged 75 years and over, residents in a care home for older adults and people aged 5 and who have a weakened immune system. In England, you are able book your booster online without waiting to be invited here. In Wales, Scotland, and Northern Ireland, you will be invited to book your booster.

Announcement by the Joint Committee on Vaccination and Immunisation (JCVI) on vaccination for young children

Children aged 6 months to 4 years in clinical risk groups to be offered COVID-19 vaccine, says the JCVI. Eligible children should be offered 2 doses of the vaccine, with an interval of 8 to 12 weeks between the first and second doses. NHS England has confirmed it will begin offering vaccinations to those eligible in England from mid-June. Parents should wait to be contacted before coming forward.

COVID Meds

From the end of June, the provision of antivirals against COVID-19 will become the responsibility of primary care, that is GPs. At that point COVID Medicine Delivery Units (CMDUs) will cease to exist. Service provision for access to all

COVID-19 therapeutics becomes the responsibility of Integrated Care Boards in England. In England, COVID-19 antivirals will cease to be covered by the prescription waiver so if you are not eligible for free prescriptions you will now have to pay a prescription charge. Immunodeficiency UK will keep you posted on developments in England and in the other three home nations as we learn more about future plans.

Prescriptions

Thank you to everyone who took part in the Prescription Coalition Survey about the impact of prescription charges on people with long-term health conditions. The survey reveals that prescription charges are a barrier to keeping people well and in work. You can read the summary report here. Find out about getting help with prescription costs here.

STRAVINSKY study

STRAVINSKY stands for ‘Stratification of Clinically Vulnerable People for COVID-19 Risk Using Antibody Testing’ This is a two-year, £2.8 million study to establish if antibody testing can identify who remains at greatest risk of severe COVID-19 infection after vaccinations. If you have been part of a previous

COVID study (OCTAVE, OCTAVE-DUO, PROSECO, CO-VAD, CORONACANCER, CLARITY, COVID-19 RENAL) the study team will contact to take part. You can also self-refer by contacting stravinsky@contacts.bham.ac.uk with your name, address, condition and specialist centre.

Visit https://www.immunology.org/partnerships/stravinsky for more information and you can follow the study on Twitter: @STRAVINSKYstudy

Cost of living crisis

Many people living with immunodeficiency may be suffering from financial hardship but there is help out there. There are many wonderful organisations that can advise on benefits and grants that could perhaps help lighten the load a little. Please do explore these websites:

Fighting UK Poverty - Turn2us
Help through Hardship - Citizens Advice
Hardship Funds - Independent Food Aid Network UK
Emergency Help If You Have No Money Or Food. StepChange

If you are thinking of claiming benefits, we can supply you with comprehensive guides from ‘Benefits and Work’ to help you fill out your forms. Get in touch with us at hello@immunodeficiencyuk.org.

‘Living with COVID’ – campaigning on behalf of the immunocompromised

We are all aware that COVID-19 has not gone away. Spearheaded by the campaign group Evusheld for the UK, Immunodeficiency UK and 18 other charities, and parliamentarians are urging Government to:

1: Ensure that a rapid system of evaluating new protective/prophylactic Covid-19 drugs and treatments is developed and implemented as a priority.

2: Reverse the decision to suspend the ONS Covid-19 Survey Data publication.

3: Ensure immunocompromised household members are included as eligible for the spring Covid-19 vaccine booster programme.

4: Ensure better communication with patients, including direct ministerial consultation with concerned charities and patient representative groups and parliamentary colleagues to ensure transparent decision making.

5: To appoint a minister with specific responsibility for the clinically vulnerable and immunocompromised.

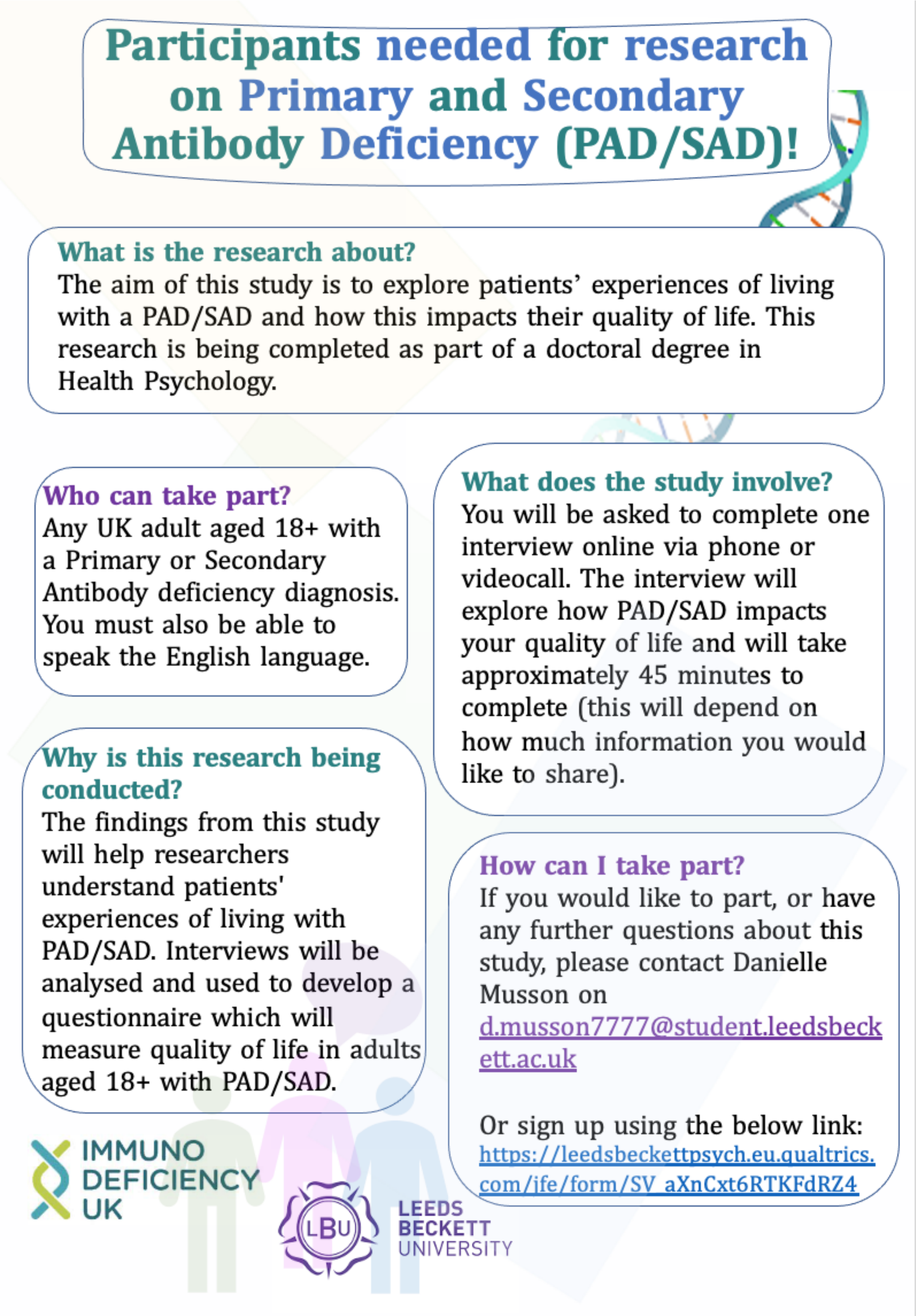
You can read the letter hand delivered by Mark Oakley, one of the founders of Evusheld for the UK, to the door of Number 10, Downing Street here.

Immunodeficiency UK is extremely grateful to Evusheld for the UK for coordinating this campaign.

IPOPI position statement on recognising primary immunodeficiency as a disability

IPOPI has released a new position statement arguing that PIDs causing a heavy burden of disease must always be recognised as a disability and that such patients should receive the necessary long-term financial and practical assistance. The fact that PIDs are rare should never result in patients being denied their right to disability support. This may be useful when trying to claim benefits.

Your help is needed for a 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/jfe/form/SV_aXnCxt6RTKFdRZ4

Researchers at Leeds Beckett University are inviting members aged 18+ diagnosed with a Primary or Secondary Antibody Deficiency (PAD/SAD) to participate in one 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. This includes, but is not limited to, Common Variable Immune Deficiency (CVID), Hypogammaglobulinemia, Selective IgA Deficiency, X-linked or autosomal recessive Agammaglobulinemia, Hyper IgM Syndrome, Specific Antibody Deficiency, disease-related secondary antibody deficiency (caused my malignancies such as leukaemia, lymphoma, multiple myeloma), and secondary antibody deficiency following treatment (e.g., steroids, radiation 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

Correction on our article on Immunology and Allergy services and Integrated Care Boards (ICBs)

In last month's newsletter we stated that 'there are no plans for the specialised services for immunology and allergy to be delegated to ICBs'. This is incorrect. Both immunology and allergy services will be moved to joint commissioning with Integrated Care Boards (ICBs), allergy services in April 2024 and immunology possibly slightly later. However, the service specifications for each of these specialist services will be set nationally, as will the policies for drugs and treatments. Apologies for our mistake.

Get involved – call for XLA affected families to take part in a survey

If your family is affected by XLA then, please consider taking part in the international survey below which is being spearheaded by Dr Maartje Blom from the Leiden University Medical Center in the Netherlands.

Dr Blom's team are investigating the potential benefits of and the best test method for newborn screening for XLA. An early diagnosis of XLA via newborn screening could lead to timely treatment shortly after birth. Early detection of XLA could prevent severe recurrent infections and complications in patients. In addition, they want to investigate whether an early diagnosis of XLA leads to improved quality of life in patients. For this, they need the help of XLA patients and parents! You can contact Dr Blom for a questionnaire at m.blom@lumc.nl.

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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