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March Newsletter

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Welcome to the March Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the March newsletter. We hope you find the information useful to you.

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

Help shape the future of mental health support
for our community

Please take part in our survey, as we want to make sure we're getting the right support out there for people living with immunodeficiency. Your answers will help us work out where to focus our efforts and how to make a real difference. It only takes 7-10 minutes to do. Your input is greatly appreciated.

The PROTECT-V clinical trial



COVID-19 continues to impact on our community, and we wanted to take this opportunity to highlight the PROphylaxis for paTIEnts at risk of COVID-19 infecTion (PROTECT-V) trial. The trial is enrolling participants who are at particularly high risk of COVID-19 and its complications, and they are looking to recruit patients who have primary or secondary immunodeficiency. The Sotrovimab arm of this trial is still open and the full eligibility criteria is on page 79 of the [trial protocol](#). We encourage you to ask your centre about being involved.

Spring 2024 COVID-19 vaccination programme

The Joint Committee on Vaccination and Immunisation (JCVI) has published the eligibility criteria for the Spring COVID-19 vaccination programme.

We encourage you to take up the offer of the Spring booster as it will help reduce the chances of you developing severe COVID-19 disease.

Eligibility

The JCVI have advised that a booster dose of COVID-19 vaccine should be offered to:

- adults aged 75 years and over
- residents in a care home for older adults
- individuals aged 6 months and over who are immunosuppressed (as defined in tables 3 or 4 (pages 23-26) in the [COVID-19 chapter of the Green Book](#)) and includes people affected by primary and secondary immunodeficiency.

Please note that people under the age of 75 years old living in the household of an immunosuppressed person will not be offered a free vaccination.

Dates:

- England: 15 April (care homes), 22 April (all other cohorts) – 30 June: [Getting a COVID-19 vaccine - NHS \(www.nhs.uk\)](#)
- Wales: 1 April – 30 June, some flexibility into July: [COVID-19 spring booster 2024 \(WHC/2024/009\).HTML | GOV.WALES](#) . The more public facing information page on COVID-19 vaccinations has yet to be updated but information should be posted at [COVID-19 vaccination information - Public Health Wales \(nhs.wales\)](#).
- Scotland – no specific dates given but information is available at [Spring coronavirus \(COVID-19\) vaccine | NHS inform](#)
- Northern Ireland – no specific dates given and the website page has yet to be updated with information but information should be posted at [Get a COVID-19 vaccination in Northern Ireland | nidirect](#).

Private vaccines will be available for the first time from April 2024 [Local private Covid vaccination service - Pharmadoctor](#).

For the latest on access to lateral tests and access to COVID-19 treatments visit our website at [Access to COVID-19 treatments - Immunodeficiency UK](#).

Going on holiday and travel insurance



The holiday season is coming, and we have been getting enquiries about which insurance companies will cover people with primary and secondary immunodeficiency. A list of travel insurance companies that people with an immunodeficiency have used successfully can be found at [Travel insurance - Immunodeficiency UK](#).

Our [insurance leaflet](#) gives you information about what questions you may be asked. Remember the insurance quote you receive is based on several different factors so there is one size fits all for the condition you have. Remember it is best to shop around to get the most competitive quote.

For other useful advice visit [Buying insurance if you're ill or disabled | MoneyHelper](#).

Our '[Going on holiday](#)' gives information to help you plan your holiday when you are affected by a primary or secondary immunodeficiency.

Insurance matters

Insurance matters

This leaflet gives information about travel and private medical insurance for individuals and families affected by a primary or secondary immunodeficiency (PID or SID). It suggests companies you might consider contacting to help you with your needs.

Going on holiday

Going on holiday

This leaflet provides information to help you plan your holiday when you are affected by a primary or secondary immunodeficiency. It gives tips for making your holiday memorable for all the right reasons.

Lucie's Story



Lucie's life changed forever when she beat blood cancer at age 27. But her battle didn't end there. Surviving chemotherapy left her with secondary immunodeficiency - hypogammaglobulinemia, a crushing diagnosis after already enduring so much. For years, fatigue and relentless infections became her new

normal. Doctors were puzzled, but thankfully, she pushed for answers. Now, she is finally on immunoglobulin replacement therapy.

Lucie has shared her unexpected journey – from cancer survivor to navigating a new health challenge. She shares lessons learned, her treatment, and the importance of advocating for yourself, even when the path is unclear.

[Read Lucie's story.](#)

Thank you Esme



We're so proud to shine a spotlight on Esme, Miss Junior Teen South Yorkshire! This inspiring young woman is not only gearing up for the Miss Junior Teen Great Britain final, but she's also a dedicated fundraiser for Immunodeficiency UK. Esme, who lives with IgA and IgM deficiency, has already raised an amazing £254 through donations and her creative Valentine's gift bags. Her bravery and determination to help others is truly inspiring.

Let's cheer Esme on! [Donate to her fundraising page](#) and help her make a difference for the immunodeficiency community.

Inspired by Esme's story? Why not fundraise for us too? [Get involved](#).



Look Good, Do Good – with Immunodeficiency
UK Tees & Vests



Get comfy, get active, and spread awareness with our awesome T-shirts and running vests! Whether you're hitting the gym or going for a walk, these are a super-cool way to show your support for Immunodeficiency UK. Plus, with every purchase, you're helping change lives. [Check them out!](#)

Funds raised from every sale go directly toward supporting the services provided by Immunodeficiency UK.

World PI Week 2024

Access to care for all PID patients, everywhere

Let's make early diagnosis & timely access to quality treatment a reality worldwide

Remembering Vicki Modell, global patient advocate, and co-founder of World Primary Immunodeficiency Week.

World PI Week
TEST • DIAGNOSE • TREAT

22-29
April 2024



www.worldpiweek.org



@world_pi_week



@WorldPIWeek



@WorldPIWeekCampaign

Help us raise awareness for 2024's World Primary Immunodeficiency Week. World PI Week is a global campaign that aims to raise awareness and improve treatment of primary immunodeficiencies (PID). It takes place from the 22nd - 29th April, and we'd love your help. This year we'll be focussing on IG therapy and raising awareness of plasma donation.

We're asking the PID community to share what a difference IG therapy makes in managing their condition. If you can please record a short video or send us a quote to use along with a photo to fay.fagon@immunodeficiencyuk.org. We'll share these across our social media during World PI week.

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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