



November
Newsletter

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Welcome to the November 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.

Progress update on our Patient Experience Survey

Thank you again for your continued patience and support with our Patient Experience Survey. As you know, this survey was 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.

We are now in the final stages of analysing the results from the survey. As we received a higher response rate to the survey than initially anticipated, this stage has taken longer to complete than we expected. We appreciate your patience and will share full details with you on how we plan to highlight the findings, once the analysis has been completed.

As a reminder, any respondents that took part in the survey will receive a £15 Amazon voucher, which will come from Takeda. Vouchers will be distributed in the coming weeks, once quality checks have been carried out. Again, owing to a larger number of respondents than anticipated, this process has taken longer than anticipated. We are in the final stages of carrying out these verification checks, so will be able to provide an update on timelines for this shortly.

If you have any questions regarding the survey or vouchers, please reach out to admin@idusurvey2023.co.uk.

Thank you again for your continued patience and support!

Keep yourself up to date on access to free lateral flow tests and COVID-19 treatments



In [last month's newsletter](#) we reported that access to free lateral flow tests (LFTS) changed in England from online access to availability through pharmacy services. We are now hearing that some people are having difficulty getting free tests from a pharmacy. We are looking into this and raising the issue with NHS England services. In the meantime, it might be helpful trying a different pharmacy if the first one you try does not have free tests. You can show the pharmacist this [fact sheet from Community Pharmacy England](#) which explains

who is at high risk from COVID-19 and therefore eligible for free lateral flow tests.

Access to COVID-19 treatments in Wales

ACCESS TO COVID-19 TREATMENTS FOR PEOPLE LIVING IN WALES

**Do you have immunodeficiency?
Have you tested positive to COVID?**

If yes to both questions, please complete this form to access COVID medicines:

<https://bit.ly/47utQU4>

scan me with your phone camera

Please also contact the Cardiff Immunology team to let them know you have tested positive.

Cardiff Immunology Centre for Wales

IMMUNO DEFICIENCY UK

0800 987 8986
immunodeficiencyuk.org

The access mechanism to COVID-19 treatments has changed in the last month.

If you get symptoms of COVID-19, you should take a lateral flow test as soon as possible. If it's positive, you will need to complete this form to access treatment: [Covid-19 Antiviral Self-Referral Form \(NHS111 Wales\)](#).

Add content for your email template in this text block.

You should then be contacted by your Local Health Board within 48 hours. If you are eligible for treatment, they will tell you how to get it. This will depend on which treatment is suitable for you.

If you can't complete the online form, call your GP or NHS111 and tell them you have COVID-19 symptoms, have tested positive, believe you are in the highest risk group and are eligible for treatment.

For more information, read the [Welsh Government's information about covid treatments](#). The [Welsh Medicines Advice Service](#) also has information about COVID treatments and how to access them.

You can find [contact numbers for each Local Health Board in Wales here](#). The Cardiff Immunology service has also asked that you contact them to let them know.

You can find more information on access to COVID-19 treatments and access to LFTs in all four home nations [here](#).



Mitch was recently diagnosed with common variable immune deficiency (CVID). He'd had symptoms suggestive of a primary immunodeficiency from an early age but was age 33 at the time of diagnosis.

The path to diagnosis started with a visit to his consultant about his bronchiectasis. By chance, he did some blood tests to check immunoglobulin levels. Days later, the results came back. His immunoglobulin level was >0.1 and he was immediately referred to a consultant immunologist at Nottingham Queen's Medical Centre. [Read Mitch's story.](#)

Lay assessors needed for the Quality in Primary Immunodeficiency Services



The Royal College of Physicians (RCP) in London is recruiting for lay assessors to join their accreditation team for the Quality in Primary Immunodeficiency Services (QPIDS) accreditation scheme. QPIDS ensures best practice standards for immunology centres.

Lay assessors are patients or members of the public with a genuine interest in the standards and improvement of clinical services. The role of a lay assessor is to represent the view of patients and the public, providing their own experience, a fresh insight, and independent perspectives to the accreditation process through hospital visits and reporting evidence.

Recruitment is open from Tuesday 21 November 2023 and will close on the Tuesday 19 December 2023.

For more information about the lay assessor role and application, please see the [link](#) or contact the RCP at accreditation@rcp.ac.uk.

Healthcare Medicines Delivery services

If you are experiencing problems with the delivery of high cost life saving medications such as immunoglobulin therapy and ancillaries, then please tell us your experience and the impact it had on you and your health at hello@immunodeficiencyuk.org. We won't be able to solve your problems directly, but we are keen to raise awareness of the issues and hold the companies involved to account.

The House of Lords has recently published a report on the need to improve to homecare medicines delivery and says 'While we welcome the current work on

homecare medicines services, we are concerned that it is vague, lacks specific commitments, and has no clear leadership. Serious problems in homecare have been apparent for over a decade. It is now time for urgent action.'

Save the date



Thanks to generous donors like you, Immunodeficiency UK can work toward our mission to support people affected by immunodeficiency. We could not do this without you, and we are truly grateful for your support and partnership in this work.

Before you step away this week to give thanks with friends and family, we invite you to give back. You can be a vital part of our journey by supporting our #GivingTuesday campaign. A donation of any size from you, even just £5, £10, can make a significant difference in supporting our mission.

This year, we've set ambitious goals, and your support is critical in helping us get there. Early donations are now open, and every contribution, even before the big day, counts toward our #GivingTuesday goals.

Mark your calendar for November 28th and join us in making an impact. Your support is invaluable in helping us with our work.

[Donate here](#)

Taking on The Three Peaks



Rachael is pictured on the right

A recently joined member, Rachael Stephens, has raised £1,225 for Immunodeficiency UK after being diagnosed with CVID earlier this year.

Rachael, who is based in Cornwall, set her sights on climbing three Scottish mountains, including Ben Nevis, the highest peak in the UK, as a fundraising challenge. A keen walker, Rachael works as a youth worker and mental health practitioner, using outdoor activities to support the people she works with.

After nearly a decade of developing various symptoms, Rachael became very unwell with an infection before Christmas last year, leading to a fraught period of tests and appointments. Rachael was referred to an immunologist when her tests showed panhypogammaglobulinemia, and she was diagnosed in February 2023.

In addition to her challenge, Rachael wanted to raise awareness of PID's and began writing a blog to document her journey through diagnosis and her progress to climbing Ben Nevis. Rachael shows an informative and candid account of her condition as well as the treatment and management she is learning to live with. She balances this with magical descriptions of her adventures in training, from the coastlines of Cornwall to the wild Scottish Munros, with a blog that is both moving and delightful. If you'd like to read it, you can find it at www.threepeakspidandme.weebly.com

Rachael smashed through her fundraising target and successfully completed her challenge at the end of September 2023.

Thank you so much Rachel for supporting Immunodeficiency UK.

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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