Welcome to the November Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member,

Welcome to the November 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.

Grifol has provided a grant for the creation of the newsletter with no input into content.

Have your say on what good care looks like for rare diseases

What does good care and treatment for rare disease mean to you?

If you are a patient, carer, healthcare professional, policymaker, or third sector professional, we need your input to develop a set of quality statements for rare disease.

To share your voice, please use the QR code, or go to rarediseaseqs.org, to complete the survey.

The Rare Disease Quality Statement project is asking the rare disease community to complete their survey, to develop a set of statements which clearly set out what high-quality, sustainable care, treatment and management look like for rare diseases.

If you are a patient, carer or healthcare professional they want to hear from you.

To complete the survey, please go to rarediseaseqs.org

If possible, please do take the time to take part. It’s key that this survey captures the insights of as many people with immunodeficiency as possible.

Introducing Annette Toft: New Trustee at Immunodeficiency UK

We’re delighted to welcome Annette Toft as one of our new trustees at Immunodeficiency UK. Annette brings not only her expertise in governance, strategy, and organisational development, but also a personal perspective as a CVID patient.

Reflecting on her journey, Annette shares, “Before 2020, I didn’t fully grasp the essential role of patient charities. But during the pandemic, Immunodeficiency UK became my lifeline. As a severely immunocompromised patient, I came to depend on their timely, accurate information and felt immense gratitude for the support they provided.”

Annette’s background is one of remarkable breadth and impact. She spent nearly 20 years in the House of Commons, advising MPs on policy, legislation, and governance, and working with various branches of government. Today, she consults as an executive coach, focusing on strategy, leadership, and organisational change. She hopes her skills will contribute to strengthening our capacity and supporting the charity’s goals of empowering patients and advocating for the immunocompromised community.

Annette shared with us that she is thrilled to join Immunodeficiency UK, not only to give back but to help ensure that our community’s needs are understood and addressed. She looks forward to working with the team to expand our impact and grow our voice in advocating for better policies, NHS services, and patient care.

She lives with her partner in the North Cotswolds which provides a wonderful backdrop to daily walks and other outdoor pursuits. She loves a good workout – especially with musical accompaniment!

We’re excited to have Annette with us and look forward to the knowledge and passion she’ll bring to the role.

Happy Birthday to the UKPID registry

Dr Ben Shillitoe, Consultant Paediatrician at Sheffield Children's Hospital, who chairs the UKPID Registry committee, gives us an update on this important patient registry:

The UKPID registry celebrates its 20th birthday in 2024. It now has over 6000 patients registered on it with either a primary immunodeficiency (PID) or secondary antibody deficiency (SAD). The work of the registry, the data it holds and the patients/families that have consented to be part of it, continue to produce high quality research that makes significant contribution to the care of patients in the UK.

Over the last 12 months, the registry has produced work on several rare conditions, including X-linked agammaglobulinemia (XLA) and Activated PI3K delta syndrome (APDS), as well as contributing to the European Society for Immunodeficiencies (ESID) registry. The valuable data held by the registry has directly assisted The National Institute for Health and Care Excellence (NICE), and the Medicines & Healthcare products Regulatory Agency (MHRA) in their decisions regarding care of PID patients in the UK.

The registry has also worked with NHS England in their designs of how PID care should look like in the UK.

Very shortly the UKPID registry will be moving, along with the ESID registry, to a new, modern database server in Europe. This new database will improve the quality of data held and make it easier to implement new studies within the registry to help a wider range of the extremely rare diseases that PID patients in the UK experience.

The UKPID registry is indebted to the patients and their families, without whom the registry simply wouldn't exist. The data collected continues to inform clinicians (UK and worldwide) of the needs for this patient group and drives changes to improve their care.

If you or your child is not part of the registry, and you would like to take part, please discuss this your Immunology team at your next appointment. Further information will be available soon once the new UKPID website https://www.ukpid-registry.co.uk is launched.

We look forward to the next 10 years of the registry and beyond, working with patients and medical groups to improve the physical health and quality of life for patients with primary immunodeficiencies and secondary antibody deficiencies.

IPOPI Leaflet: PIDS and Respiratory Disorders

Respiratory disorders are a common issue for those living with immunodeficiency.

Recurring infections, chronic lung conditions, and other breathing related complications can greatly impact the health and quality of life for immunodeficiency patients.

Take a look at this IPOPI leaflet titled "PIDS and Respiratory Disorders." This comprehensive guide covers:

- The different types of respiratory disorders seen in immunodeficiency patients, including infections and non-infectious complications
- Common respiratory symptoms to watch out for
- The importance of regular respiratory evaluations and monitoring
- Treatment options for managing respiratory issues
- Tips for preventing the spread of infections

This valuable resource is available on the Immunodeficiency UK website. It is a great way to raise any respiratory health problems with your GP.

Celebrating Sophie and Micky's Incredible 870-Mile Challenge for Immunodeficiency UK

We're thrilled to honour Sophie and Micky's incredible accomplishment as they completed an 870-mile trek along the beautiful Wales Coast Path. This epic journey took them across rugged cliffs, sandy beaches, vibrant cities, and peaceful towns—all to raise awareness and much-needed funds for Immunodeficiency UK.

Sophie's motivation comes from a deeply personal place. Her son, Jasper, was recently diagnosed with APDS, a rare immunodeficiency, after years of unexplained health challenges. Determined to make a difference, Sophie and Micky set out on this extraordinary adventure, walking mile after mile in support of individuals like Jasper who live with immunodeficiency.

Their journey was nothing short of inspiring, and they raised an impressive £2,485, far exceeding their initial goal. Every donation will help provide essential support, resources, and hope to families navigating life with immunodeficiency.

Thank you, Sophie and Micky and thank you to all who supported them along the way! If you'd like to learn more or contribute to their cause, visit their fundraising page here: https://www.justgiving.com/page/sophie-micky-mightyhike

STRAVINSKY COVID-19 Research Study: Watch the Latest Update

Did you miss the important British Society for Immunology STRAVINSKY study webinar in October? You can now catch up on this valuable research that impacts our community. The webinar recording is available to watch at https://www.youtube.com/watch?v=gDMSKza3xcw

This is your opportunity to:

- Learn about the latest findings
- Understand how the research may impact vulnerable individuals

JCVI announces COVID-19 vaccination recommendations for 2025 and spring 2026

The Joint Committee on Vaccination and Immunisation (JCVI) statement has outlined recommendations for the 2025 and spring 2026 vaccination programme.

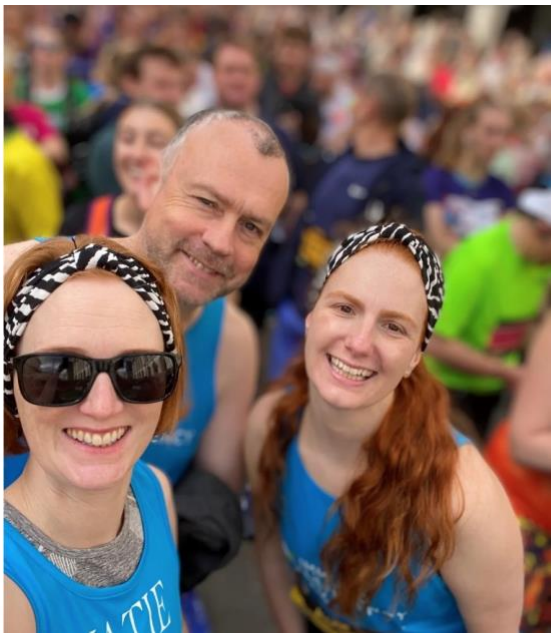
The advice is based on cost-effectiveness assessments with the target groups identified as adults aged 75 and over, residents in older adult care homes, and individuals aged 6 months and older who are immunosuppressed with an increased risk of getting seriously ill from COVID-19 because of a health condition or treatment. People with a primary or secondary immunodeficiency would fall under this latter category.

Read more about the rationale used to decide who gets offered an NHS COVID-19 vaccination at JCVI statement on COVID-19 vaccination in 2025 and spring 2026 - GOV.UK

Remember: you have until the 20th December to book your winter 2024 COVID19 vaccination.

A vaccination interval of approximately six months after your last dose is recommended although a minimum interval of three months is allowed.

Run the London Landmarks Half Marathon for Immunodeficiency UK!



Looking for a meaningful challenge in 2025? Join Team Immunodeficiency UK for the London Landmarks Half Marathon and take on 13.1 miles through the heart of London, passing iconic sites like Big Ben, the Tower of London, and Buckingham Palace!

By running for us, you'll be raising vital funds to support those living with immunodeficiency. Your contribution will help fund essential services and raise awareness for individuals facing immunodeficiency.

As part of Team Immunodeficiency UK, you'll receive:
- A guaranteed race entry (no ballot needed!)
- Resources to help you meet your fundraising goals
- An Immunodeficiency UK running vest or t-shirt

📅 Date: 6 April 2025
💷 Minimum Sponsorship: £350

Whether you're an experienced runner or new to half marathons, this is a great way to make a difference. Secure your spot today and help us create a brighter future for those affected by immunodeficiency.

Katie, Andy and Jackie ran for Immunodeficiency UK last year, read more about their experience here.

Visit our dedicated London Landmarks Half Marathon page for more information

Best wishes,
Susan and Fay
The Immunodeficiency UK Team