Welcome to the August Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member,

Welcome to the August 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.

Autumn COVID-19 booster programme

Information has now been released concerning the COVID-19 Autumn booster programme.

Eligible groups for COVID-19 boosters this autumn are:

- adults aged 65 years and over residents
- in a care home for older adults
- individuals aged 6 months to 64 years in a clinical risk group (as defined in tables 3 or 4 in the COVID-19 chapter of the Green Book)

The eligibility is the same across the 4 nations of the UK (England, Scotland, Wales and Northern Ireland).

Current vaccines provide good protection against severe disease and hospitalisation. UK Health Security Agency (UKHSA) surveillance data relating to last autumn’s programme shows that those who received a vaccine were around 45% less likely to be admitted to hospital with COVID-19 from 2 weeks following vaccination, compared to those who remained unvaccinated.

Health providers have been told that they should work on the basis that the COVID-19 and adult flu programmes will commence in early October. We will keep you informed.

More information can be found at:

NHS England » Preparations for an Autumn/Winter 2024/25 flu and COVID-19 seasonal campaign

Who's eligible for the 2024 COVID-19 vaccine, or 'Autumn Booster'? – UK Health Security Agency (blog.gov.uk)

Access to free COVID-19 lateral flow tests and COVID-19 medicines

You can find recently updated information on these topics at Access to COVID-19 treatments - Immunodeficiency UK

COVID-19 surveillance data (cases, hospital admissions) can be found at COVID-19 | UKHSA data dashboard. The UKHSA provides updates every week on a Thursday at 4pm.

Integrated Care Boards and making a complaint

We understand that access to COVID-19 medicines via some local Integrated Care Boards (ICBs) in England, is not working as smoothly as it should. If you have had a bad experience and want to complain or just want to give feedback, then contact your local ICB. NHS England » Contact your local integrated care board (ICB)

If you're not sure which ICB to contact you can do a postcode search on the NHS Organisation Data Service website. The name of the ICB appears under 'Higher Health Authority.'

How to make a complaint about healthcare - Immunodeficiency UK

Update on Rare Disease plans and tackling delays to diagnosis

Specialised Healthcare Alliance
FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

Measuring progress one year on

Navigating the labyrinth: reducing delays to a rare disease diagnosis

The Specialised Healthcare Alliance (SHCA), of which Immunodeficiency UK is a member, has published a new report It analyses the progress made over the past year against existing government actions and commitments – ‘Measuring progress one year on’. The report shows there is still much work to be done.

The intention behind this new report is to celebrate successes made over the past year and hold policymakers to account where progress has been too slow or held up.

The report grades progress across England, Wales, Scotland and Northern Ireland against the themes of their original report which explored the impact of delays to a rare disease and made 10 recommendations to reduce long waits.

The Scottish Government has recently published a report outlining the steps that have been taken to implement Scotland’s Rare Disease Action Plan. The report acknowledges that there is much more to be done to improve the lives of and includes a renewed priority list for action in 2024/25.

Together we are stronger!

Immunodeficiency UK supports the Genetic Alliance UK campaign calling on the new government to commit to building on the current UK Rare Diseases Framework by setting new ambitions for improving the lives of people with rare conditions over the next five years.

Read their open letter and get involved in their campaign.

Make your voice heard

Please consider taking part in the EURODIS Rare Barometer survey on the impact of rare diseases on everyday life. The survey is open worldwide to patients and families affected by rare conditions such as immunodeficiency.

The survey closes on the 8 Sept 2024.

Celebrating the "Immunology Runners" Healthcare Heroes for Immunodeficiency UK

We are overjoyed to report that a dedicated team from the Salford Immunology Service (Northern Care Alliance) recently took Manchester by storm, running the 10km Great Manchester Run to raise crucial funds for Immunodeficiency UK.

Led by the tireless efforts of Lucy Common, Nurse Consultant, this inspiring group - also including Dr. Sai Murng (Consultant Immunologist), Ivonette Jones

(Senior Nurse Specialist), and Michael Common (Lucy's husband) - proudly dubbed themselves the "Immunology Runners."

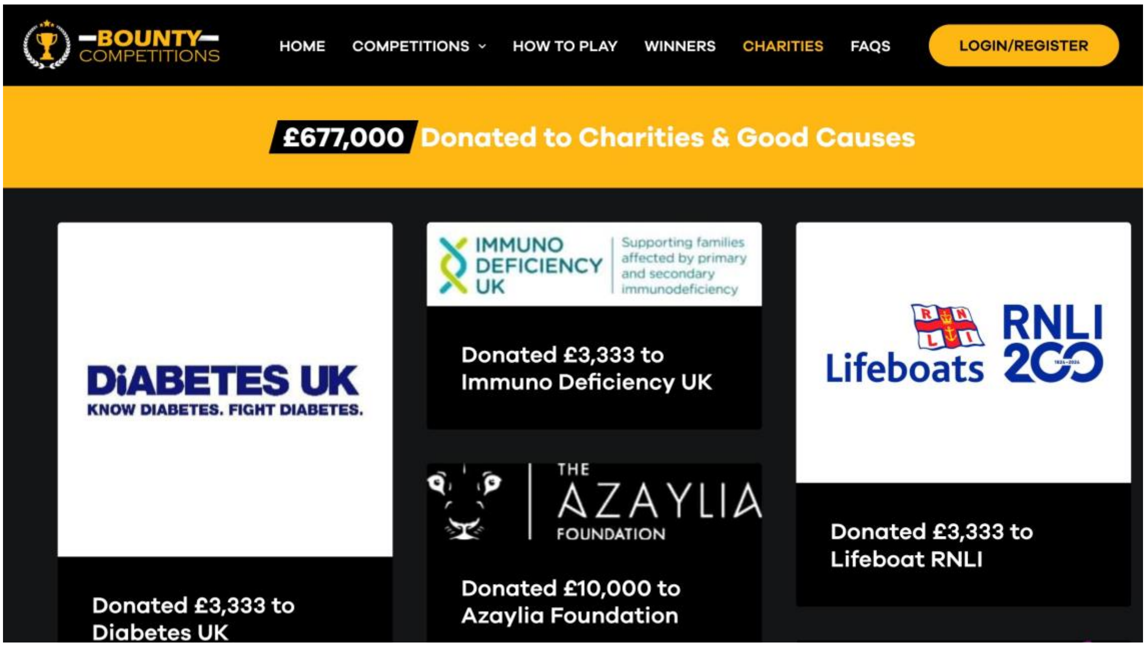
With the goal of raising £500 for our charity, this team of healthcare heroes set out on a sunny day in May to conquer the bustling city streets. Lucy shared that as professionals who value the support Immunodeficiency UK provides their patients, they were honoured to give back through this challenge.

"*There was a great atmosphere as we ran through the centre of Manchester and up to Old Trafford and back,*" Lucy recounted. "*We very much enjoyed the support of the crowd which kept us going for the run.*"

We are thrilled to share that the Immunology Runners met their £500 target.

Every step taken and every pound raised will make a difference in the lives of individuals and families impacted by immunodeficiencies. On behalf of the entire Immunodeficiency UK team, we extend our heartfelt gratitude to the "Immunology Runners". Thank you for your support - it is making a vital impact.

A Heartfelt Thank You to Bounty Competitions for Supporting Immunodeficiency UK



£677,000 Donated to Charities & Good Causes

Donated £3,333 to Diabetes UK

Donated £3,333 to Immuno Deficiency UK

Donated £10,000 to Azaylia Foundation

Donated £3,333 to Lifeboat RNLI

We are incredibly grateful to announce that Bounty Competitions has generously donated £3,333 to help us provide support to families affected by primary and secondary immunodeficiency.

This generous contribution will make a significant impact in helping us continue our mission of advocating for those living with immunodeficiency.

Ensuring a Smooth School Year for Students with Immunodeficiencies

As families and schools prepare for the return to classes, Immunodeficiency UK wants to ensure students living with primary immunodeficiency (PID) have the support they need to thrive academically and socially.

To that end, we wanted to share a valuable resource developed by our international partner, the International Patient Organisation for Primary Immunodeficiencies (IPOPI).

This informative booklet covers a range of important topics, including:

- Preventing infections through good hygiene practices
- Facilitating vital treatments like immunoglobulin infusions during the school day
- Empowering students to participate safely in physical activities
- Minimising the impact of absences on their education
- Fostering inclusive peer relationships and addressing stigma

By equipping schools with this knowledge, we aim to create an environment where children and adolescents with PIDs can focus on learning and enjoying their school experience - rather than worrying about managing their health condition.

We encourage you to share this guide with teachers and school nurses in your child's school. Download the IPOPI booklet here.

Ask your MP to call for a review of prescription charges in England

If you or a loved one are living with an immunodeficiency disorder in England, we know the financial burden of affording vital medications can be overwhelming. Many individuals with long-term conditions like primary and secondary immunodeficiencies are not included in the NHS exemption list for prescription costs, leaving you to shoulder these critical expenses.

This is simply unacceptable. We at Immunodeficiency UK believe everyone deserves access to the treatments they need to manage their condition. That's why we're urging you to take action. Please reach out to your Member of Parliament (MP) and call on the Care Minister, Stephen Kinnock, to urgently review the exemption list. Your voice can make a real difference in driving the changes necessary to support the immunodeficiency community.

Use this link to easily contact your MP and share your story:
https://campaign.parkinsons.org.uk/page/154293/action/1

Find out if you qualify for free prescriptions in England and help with prescription costs at Prescription charges and immunodeficiency - Immunodeficiency UK

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team