



Welcome to the April Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we update you on the COVID-19 spring vaccination programme, give thanks to our amazing fundraisers and another chance to sign up for our dealing with diagnosis webinar.

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.

Spring COVID-19 vaccinations

A vertical poster with a dark blue background and a light green horizontal band. The top section features the UK Health Security Agency logo and the NHS logo. The main text 'Top up your protection this spring' is in large white font. The middle section, on a green background, states that immunosuppressed individuals might be eligible for the spring COVID-19 vaccine offer. The bottom section, back on the dark blue background, provides a link to find out more and book online at nhs.uk/get-vaccine.

UK Health Security Agency

NHS

Top up your protection this spring

Those who are immunosuppressed might be eligible for the **spring COVID-19 vaccine offer**

Find out if you're eligible and book online at **nhs.uk/get-vaccine**

The NHS national booking system has opened for eligible people to book their spring COVID-19 vaccination.

You can get a COVID-19 vaccine if you:

- are aged 75 or over (including those who will be 75 by 17 June 2025)
- are aged 6 months to 74 years and have a weakened immune system because of a health condition or treatment
- live in a care home for older adults

In England, you can book your [appointment online now](#).

In Scotland and Wales, letters, texts and emails are being sent to invite eligible people to book.

Appointments in [Northern Ireland can be made online](#) now.

For more information visit: [Spring 2025 COVID-19 vaccination programme - Immunodeficiency UK](#).

Chris's story on the benefits of fly fishing



Christopher Meadows, a long-time member of Immunodeficiency UK, will be representing England in the Four Nations flyfishing competition in May 2025 being held on Lough Erne, Northern Ireland. He got in touch with us in February and wanted to share how this activity helps him cope with his condition common variable immunodeficiency (CVID).

Chris was diagnosed with CVID in 1998 and has found fly fishing valuable to his health and mental wellbeing.

This form of outdoor therapy, casting a fly line from the comfort of a lough boat suits his physical capabilities and provides very gentle activity without exhausting his limited stamina.

The UK Department of Health recommend leisure activities that give a balance of mental and physical wellbeing. Flyfishing provides a form of gentle physical exercise improving cardiovascular health, stress relief and mindfulness meditation while sunlight promotes production of vitamin D essential for bone health.

Chris says that for him, the dynamics of fly fishing provide a healing connection to the natural world, relieving everyday stress and promoting a sense of calm. Fly fishing techniques provide a gentle exercise for joint and soft tissue mobility, and requires no strength so is perfectly safe and comfortable. Chris

highly recommends trying out flyfishing for all of the above, but most importantly it is about social engagement and having fun.

The England Disabled Fly-fishing Charity run monthly fly-fishing days. Visit www.englishdisabledflyfishers.org.uk for more information.

We wish Chris every success at the competition.

Do you have a hobby that helps you cope with your condition that you would recommend to others, then let us know at hello@immunodeficiencyuk.org.

Last chance to sign up for our dealing with diagnosis webinar



Dealing with Diagnosis: making time for you and your feelings

An online workshop for those diagnosed within the last 3 years

Date: Tuesday 22nd April 7pm - 9pm
Location: Zoom

When you first receive a diagnosis of an immunodeficiency, the focus can often be on the practical and physical implications. There may not always be the time to work through the emotional impact of receiving a diagnosis.

Part presentation, part interactive workshop, this small supportive group of up to 20 participants is facilitated by Rareminds Counsellor, Rebecca. It offers a friendly, informal opportunity to discuss together how you felt (and feel) about the impact of an immunodeficiency on your life and relationships with others who will share similar experiences.

"Being able to share our story and hear we are not alone in this journey was really helpful." (Dealing with Diagnosis workshop participant)

If you would like to know more about this workshop or make contact with the Facilitator in advance, please contact Rebecca (Rareminds Specialist Counsellor) on rebecca@rareminds.org



Rebecca Hargreaves MBACP (Accred.)

is an Adult and Young Peoples Counsellor with a particular interest in the psychological impact of health conditions on the family as a whole. She originally worked as a Nurse for over 20 years including in hospices, and is the former Lead for a large schools counselling service. She works as a counsellor with several rare disease patient organisations.

To reserve your place please email Immunodeficiency UK at hello@immunodeficiencyuk.org

We look forward to seeing you there!

Dealing with Diagnosis: Making Time for You and Your Feelings

This is an online workshop for those who have been diagnosed within the last 3 years.

Date Tuesday, 22nd April

Time 7:00 pm – 9:00 pm

Location Zoom

This webinar workshop, facilitated by Rareminds counsellor Rebecca Hargreaves, offers a blend of presentation and interactive discussion. It provides a safe and supportive space for up to 15 participants to explore and share their feelings about the impact of immunodeficiency on their lives and relationships. This webinar is aimed at helping with the emotional aspects of dealing with a new diagnosis and not the medical aspects of your condition, its treatment, or its management.

Testimonial from a Previous Participant

“Great session, really enjoyed listening to others experiences of living with a chronic condition and how it has impacted them personally and professionally.”

To reserve your place for this valuable workshop, please email us at hello@immunodeficiencyuk.org with a short paragraph on why you think this workshop would benefit you.

Each workshop place costs our charity £60, so we ask that you please notify us promptly if you can no longer make it so we can offer your spot to another participant.

We encourage you to secure your spot as soon as possible, as places are limited. We look forward to seeing you at the workshop.

A Huge Thank You to Our London Landmarks Half Marathon Runners!



We want to extend our thanks to all the amazing runners who took on the London Landmarks Half Marathon recently in support of Immunodeficiency UK. Your dedication, energy, and generosity mean the world to us—and to the individuals and families living with immunodeficiency.

Thanks to your incredible efforts, not only did you conquer 13.1 miles through one of the most iconic routes in the capital, but you also helped raise over £3,500 to support our mission.

Every step you took brings us closer to a future where everyone with an immunodeficiency gets the support and advice they deserve.

From all of us at Immunodeficiency UK— **thank you**. You truly are champions!

Get ready for World Primary Immunodeficiency Week—let's raise awareness together!



World Primary Immunodeficiency Week (World PI Week) is just around the corner, and at **Immunodeficiency UK**, we're gearing up to shine a light on the challenges faced by people living with primary immunodeficiency. This year's event takes place on the 22nd–29th April.

We need **your help** to make an impact.

Here's how you can get involved:

- **Follow our campaign** on Facebook, Instagram and Bluesky.
- **Share our posts and stories** to help raise awareness.
- **Comment on our posts** so our awareness content can reach even more people.

Every share, like, and conversation helps us take a step closer to better understanding, faster diagnosis, and improved care.

Let's make World PI Week 2025 unforgettable.

Blanche completes the RomaOstia Half Marathon



In March 2025, Blanche ran the RomaOstia Half Marathon to raise vital funds for Immunodeficiency UK and LaSpes ONLUS, who support research into rare genetic diseases like Wiskott-Aldrich syndrome (WAS).

Blanche's close friends lost their son to WAS, and she ran in his memory.

Twenty-five percent of the total funds raised went to Immunodeficiency UK, and to date Blanche has raised over £380 to support our work.

Blanche ran 13.1 miles, and the route took her through the beautiful EUR district of the city to the finish point near the beaches of Ostia. It is Italy's most popular half-marathon.

From all of us at Immunodeficiency UK, thank you, Blanche; we appreciate your support.

Would you like to support our work too? Why not fundraise for us and contribute to Immunodeficiency UK's vital work supporting individuals and families affected by immunodeficiency?

Huge thanks to the Jeffrey Modell Foundation



Immunodeficiency UK was delighted to be awarded a World Immunodeficiency Network (WIN) grant from the Jeffrey Modell Foundation. The grant will help meet the printing costs of our booklets on immunoglobulin therapy.