IMMUNO DEFICIENCY UK

August
Newsletter
2025

Welcome to the August Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we tell you more about our latest collaboration, how to join our peer support event and information on new resources we have developed for successfully navigating the NHS.

Read on for our monthly news round up and you can get updates throughout the month by visiting us on Facebook.

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

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We are delighted to announce that we are collaborating with D-CYPHR (the DNA, Children + Young People's Health Resource) part of the NIHR (National Institute for Health and Care Research) BioResource and NHS.

The aim is to get more families involved in health research that could help improve our understanding and develop new treatments for many conditions, including immune diseases.

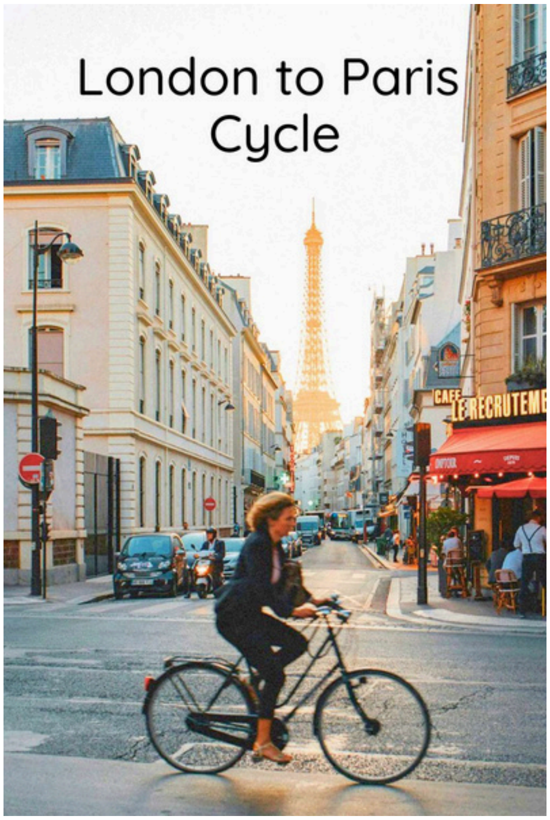
The more people with a certain condition who join D-CYPHR, the more research they can facilitate in areas that might benefit our community in the future. D-CYPHR are looking for participation from all children and young people regardless of whether they have medical conditions or not – effective health research depends on inclusion of all.

The programme is open to any child and young person aged 0 –15 in the UK. The decision to join is voluntary and, for ages 6+, it is made by parent/guardian and child together.

Visit the D-CYPHR website for more information about the programme and how to sign up.

NIHR BioResource recently published a blogpost that details why this collaboration is important. Read it here.

Pedal with purpose: London to Paris for Immunodeficiency UK



Are you ready for an unforgettable adventure?

Join the **London to Paris Cycle** Challenge and support **Immunodeficiency UK**.

Over four incredible days, you'll cycle from the heart of London to the iconic Eiffel Tower, covering 300 miles, building lifelong memories, and raising essential funds to help people living with primary or secondary immunodeficiency.

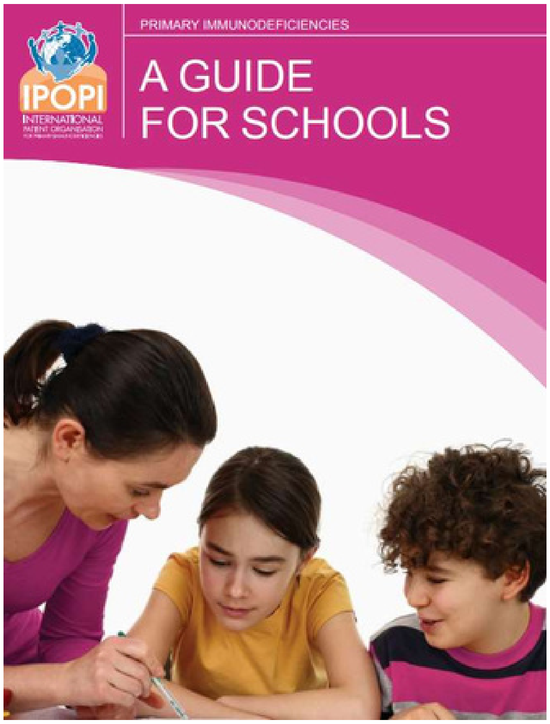
When: Choose your 2026 date
Where: London → Paris
Why: Every pound you raise helps provide life-changing support to families navigating the challenges of immunodeficiency.

Whether you're a seasoned cyclist or looking for a new challenge, you'll be fully supported along the way with expert guides, accommodation, meals, and a celebration in Paris!

Places are limited—sign up today and ride for a cause that truly matters.

Join the challenge now »

Guide for schools: supporting pupils with immunodeficiency



IPOPI
INTERNATIONAL PATIENT ORGANISATION

PRIMARY IMMUNODEFICIENCIES

A GUIDE
FOR SCHOOLS

Navigating school life with an immunodeficiency can be challenging, for both children and their families. That's why we're sharing IPOPI's guide to help schools provide the care, understanding, and flexibility pupils with primary immunodeficiency (PID) need to thrive.

This guide offers practical advice for school staff, including:

- What PID is and how it affects children
- Supporting emotional wellbeing and reducing isolation
- Managing infection risks
- Planning for absences, hospital stays, and fatigue

Share this guide with your child's school to help them build a safe and inclusive school environment.

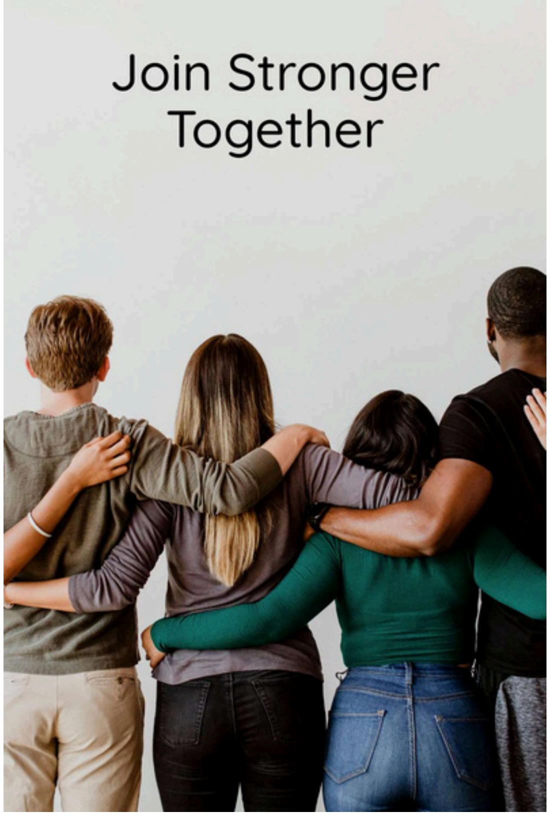
Download now:
Click here to access the guide (PDF)

Or email hello@immunodeficiencyuk.org to request a printed copy.

By raising awareness and understanding in schools, we can make a real difference to the education and wellbeing of children living with immunodeficiency.

New peer support group starting 17th September – join Stronger Together

Living with a primary or secondary immunodeficiency can feel isolating at times — but you don't have to navigate it alone.



Stronger Together is a supportive, confidential peer group offering you space to share your experiences, challenges, and triumphs with others who truly understand. Facilitated by Rareminds, this unstructured 8-week group offers practical and emotional support in a safe, welcoming environment.

The topics discussed will vary, depending on group members and their particular needs but will not be able to deal with medical queries. This group is for those with a diagnosed immunodeficiency only.

Starts: Wednesday 17th September
Time: 6:00 – 7:30 PM
Duration: Weekly meetings for 8 weeks

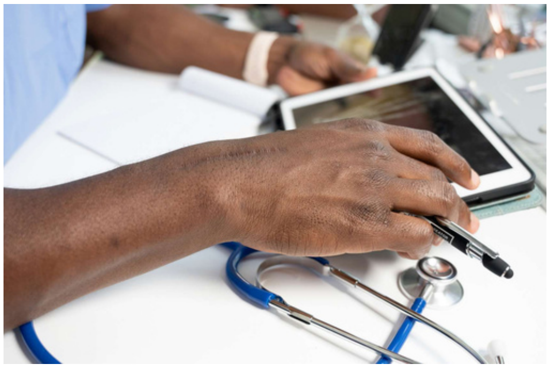
Each session allows you to connect, talk openly, and build bonds with others living with similar challenges.

Although we understand 'life happens', please be prepared to commit in principle to all 8 sessions to make the most of the experience.

Reserve your place now – spaces are limited.

Email us stating your diagnosed immunodeficiency to hello@immunodeficiencyuk.org to sign up.

Information to help you navigate the NHS



At Immunodeficiency UK, we’re here to empower you with the knowledge and confidence to advocate for your health.

That’s why we’ve developed new information to help:

Know your rights: navigating the NHS as a patient

Understanding your rights as a patient can make all the difference. This practical guide helps you feel informed, prepared, and supported every step of the way.

Read the guide

Accessing and amending your medical records

You have the right to view and update your medical records — but how do you go about it? This helpful resource explains your rights, how to request access, and what to do if something needs changing.

Learn more here

These resources are designed to help you feel more in control, more informed, and better supported.

The shingles vaccine programme

Immunodeficiency UK has been informed by NHS England (NHSE) about the widening of the eligibility criteria for the shingles vaccine programme from the 1st of September 2025.

Based on the latest advice from the Joint Committee on Vaccination and Immunisation (JCVI), eligibility for the NHSE Shingles vaccination programme will change to allow all severely immunosuppressed people aged 18 years and over to receive the shingles vaccine.

NHSE has published a joint letter with the UK Health Security Agency regarding the changes.

Severely immunosuppressed people will be offered two doses of the non-live shingles vaccine, Shingrix®, with the second dose given 8 weeks to 6 months after the first dose for this cohort, in line with the Summary of Product Characteristics (SmPC)

Eligibility includes:

- Individuals with primary or acquired immunodeficiency
- Individuals on immunosuppressive or immunomodulating therapy
- Individuals with chronic immune-mediated inflammatory disease who are receiving or have received immunosuppressive therapy

More details on eligibility can be found on page 7 of the Shingles Green Book chapter 28a.

Getting the vaccine will reduce your risk of developing shingles, long-term pain from shingles, and the risk of being hospitalised from the complications of having shingles.

NHS England has informed us that the vaccination will be available via GP practices from the 25th of September, and they are requesting that individuals wait to be invited by their practice to come forward for the jab. However, if later in the year, an eligible individual feels they may have been missed out by mistake, they can proactively reach out to their GP practice to check in.

Your medical team is best placed to answer any specific questions that you may have about this vaccination programme.

We will keep you informed of the programmes in other home nations as we learn more.

Wear your support with an Immunodeficiency UK pin badge

Looking for a simple way to make a statement in support of immunodeficiency awareness?

- Durable enamel pin with Immunodeficiency UK logo
- Vibrant colours and high-quality design
- Perfect for customising jackets, bags, hats, and more
- Affordable at £2 each + 79p postage
- Proceeds support our advocacy and services

You can order one now.

Thank you for standing with us—together, we can make every small action count.

Finally, we give huge thanks to our amazing community of supporters, families, and individuals living with immunodeficiency. Your continued support makes a world of difference. You inspire us, and we couldn’t do what we do without you!

Best wishes,
Susan and Fay
The Immunodeficiency UK Team