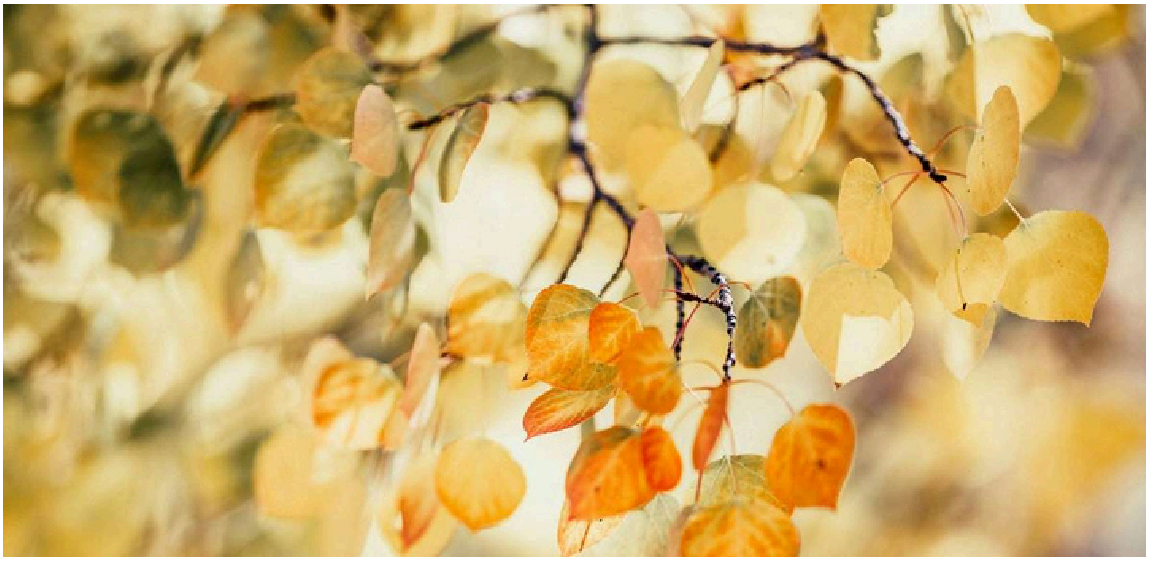
Welcome to the September Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the Immunodeficiency UK newsletter. This month we share information on the SCID newborn screening consultation, cover a new report on inequalities in COVID-19 treatments and provide an update on our latest advocacy activities.

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.

SCID newborn screening recommendation and consultation

The UK National Screening Committee (UK NSC) has launched a consultation on its proposed recommendation to continue the in-service evaluation (ISE) of newborn screening for severe combined immunodeficiency (SCID) in NHS services.

The evaluation started in September 2021 to answer important questions about the impact and effectiveness of screening for this condition.

SCID screening, as part of the newborn blood spot (NBS) screening programme, looked for babies with low numbers of white blood cells as a sign that they may have the condition. Early detection allows for steps to be taken to prevent the risk of infections, which can be life-threatening to babies with SCID. Early diagnosis also improves the success of a bone marrow transplant, which can be an effective curative option.

During the evaluation period to March 2024, over 1 million babies were screened for SCID, and during this period, screening detected 10 babies with SCID who would otherwise have gone undiagnosed until infections developed, thus preventing serious illness and saving lives.

You can read about the experiences of families affected by SCID through these family stories:
My family and SCID by Jennifer - Immunodeficiency UK
SCID and my family by Rebecca - Immunodeficiency UK

The recommendation

The latest evidence on screening for SCID, including NHS England's (NHSE's) assessment, was presented to UK NSC members at their June 2025 meeting. The evidence presented showed that although the screening test detected babies who had SCID, it also detected hundreds of babies with low white cell numbers who were subsequently found to be well. Babies in this group therefore derived no benefit from screening. and many families were put through the stress of being told their baby may have a life-threatening disorder, when this turned out not to be true. Work to reduce the detection of these 'false positives' remains ongoing.

Furthermore, the cost-effectiveness study estimates that screening for SCID greatly exceeds the currently accepted cost-effectiveness thresholds, as a standalone addition to the NBS screening programme. However, the report estimates that SCID screening would become cost-effective if screening for the condition spinal muscular atrophy (SMA), was introduced or trialled at the same time, using the same testing system.

The UK NSC decision, for the reasons above, was not to recommend a national rollout of SCID newborn screening but to recommend extending the evaluation period for SCID while an ISE of newborn screening for spinal muscular atrophy (SMA) takes place.

The consultation

The UK NSC are now asking organisations and individuals, including members of the public, to provide feedback on the consultation evidence documents and the recommendation. Immunodeficiency UK will be preparing a response, and we would like to hear your views based on reading the evidence documents below. You can get in touch with us at hello@immunodeficiencyuk.org

You can also respond directly to the consultation by clicking on the grey 'View documents' button on the UK NSC's SCID recommendation page. Submitting your response by clicking on the green 'Submit comments' button.

The deadline for responses is the 27 October.

The evidence documents used for the recommendation can be downloaded from the following links:

- UK NSC covernote that includes the recommendation to extend the ISE
- 2025 evidence review of newborn screening for SCID
- NHS England report on the findings of the ISE
- 2025 Sheffield Centre for Health and Related Research (SCHARR) modelling study on the cost-effectiveness of screening for SCID in the UK.

COVID-19 vaccination

You can now book your Autumn COVID-19 vaccination for appointments from the 1st October. Visit: Book, change, or cancel a COVID-19 vaccination appointment online - NHS

For information on COVID-19 vaccine eligibility criteria visit: Autumn/Winter COVID-19 vaccination programme 2025 - Immunodeficiency UK

Access to COVID-19 medicines

During this autumn and winter season, we are likely to see an uptick in respiratory infections caused by COVID-19. Do make sure you are prepared with the information you need to access COVID-19 therapeutics should you test positive for COVID. Information is available at Access to COVID-19 treatments - Immunodeficiency UK

Member testimonial

"*I wanted to express my gratitude to Immunodeficiency UK for the wealth of information that you provide, both on your very comprehensive website, through your engaging newsletter and the various events that you set up or support. I was diagnosed with primary antibody deficiency about 9 years ago but I am still learning about my condition and the other health issues that are sometimes associated with it. I have found Immunodeficiency UK's website extremely useful to help support my learning process and reassure me about some test results, especially as some of these 'other' health issues may not have an obvious connection to primary immunodeficiency – or at least from a patient's point of view. For example, I have found the patient leaflet on CVID very helpful, as well as just being able to do some simple keyword searches on the website, which led me to the exact information I was looking for. Thank you very much for all your support, Immunodeficiency UK, for making such an impact on the lives of individuals living with immunodeficiencies and their families!*" **Dominique**

Free public webinar on the STRAVINSKY study

The STRAVINSKY team is hosting a free public webinar on **Tuesday 21 October, 6pm–7pm**. This session will share the latest progress and findings from the study, along with an update on the current COVID-19 situation for people with weakened immune systems.

Reserve your place now to take part.

Register for free

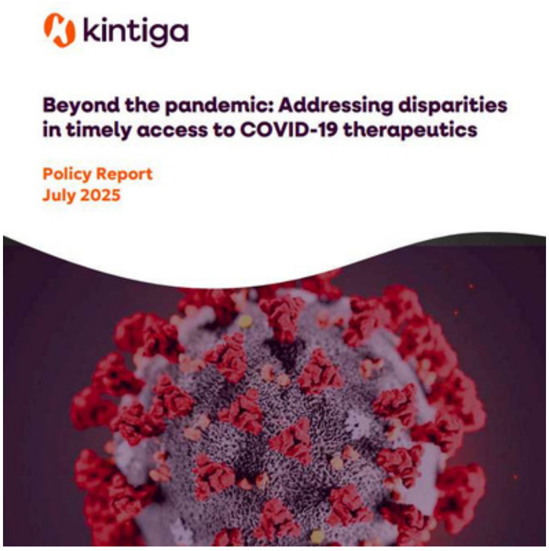
Questions can be submitted in advance through the registration link or asked live during the webinar. All questions will remain anonymous. Please note: the team cannot provide answers on individual medical concerns.

About the STRAVINSKY Study

The STRAVINSKY (Stratification of Clinically Vulnerable People for COVID-19 Risk Using Antibody Testing) study was started in 2023. It aims to further understanding of who is most clinically vulnerable to COVID-19 infection and identify individuals or disease groups at highest risk. Using this information, STRAVINSKY hopes to assess the effectiveness of COVID-19 booster vaccine programmes or new treatment strategies for these groups.

Questions can be submitted in advance through the registration link or asked live during the webinar. All questions will remain anonymous. Please note: the team cannot provide answers on individual medical concerns.

Disparities in access to COVID-19 therapeutics



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Beyond the pandemic: Addressing disparities in timely access to COVID-19 therapeutics

Policy Report
July 2025

A new report reveals ongoing inequalities in how COVID-19 treatments are reaching immunosuppressed and clinically vulnerable people. Many patients have faced delays, unclear referral pathways, and regional differences in availability, leaving them at greater risk.The findings confirm what we are hearing through our helpline.

The findings highlight the urgent need for better communication, streamlined access, and consistent support across the NHS.

Read the full report on our website

Immunodeficiency patients receiving treatments made from UK plasma

NHS Blood and Transplant (NHSBT), NHS England, the Department of Health and Social Care, and hospitals across the country are celebrating a significant milestone, with 2,221 NHS patients now treated with lifesaving immunoglobulin made from UK plasma.

The first patients began receiving treatment in March 2025 — marking an important step toward securing a reliable, homegrown supply for those who rely on immunoglobulin to stay well.

Samantha Bloomfield, who suffers from Common Variable Immunodeficiency (CVID) was featured in the NHS Blood and Transplant press report, says the treatment has been “life-changing”:

"It is incredible to think that I'm receiving this treatment made from the plasma of UK blood donors. Knowing that we now have this ability in the UK gives peace of mind for the future, not just for me, but for all patients reliant on regular IVIG infusions. I feel extremely grateful to all the donors who make these treatments possible."

Our CEO, Dr Susan Walsh, welcomed the news:

"For patients with primary and secondary immunodeficiency, plasma-derived medicines provide a vital lifeline. Having a UK supply means greater security for patients who rely on immunoglobulin to stay well and highlights the generosity of UK donors whose plasma is being transformed into life-saving therapies. Immunodeficiency UK welcomes this progress and thanks every donor whose gift is helping to protect the lives of people living with immunodeficiency."

Read more about this exciting milestone →

Wear your support: grab our charity pin badge for just £2

Raise awareness about immunodeficiency with our exclusive Immunodeficiency UK pin badges! Stylish and eye-catching, these high-quality enamel pins are the perfect way to showcase your support for Immunodeficiency UK and those living with primary and secondary immunodeficiency.

Whether you choose to adorn your jacket, bag, or hat, these pins will let you wear your support with pride. Buy it here

Top 10 research priorities for paediatric HSCT

Immunodeficiency UK is proud to have been a collaborative partner with the Murdoch Children's Research Institute and the James Lind Alliance in developing the top ten research priorities for paediatric haematopoietic stem cell transplants (HSCT).

This important piece of work was shaped by the voices of patients, families, and clinicians, ensuring that the areas of greatest need and impact are placed at the forefront of future research.

We are honoured to have supported this important work and give thanks to the research team and the many families who contributed their experiences and insights.

Read the 10 research priorities

Your voice can SHAPE the future of PID research

IPOPI are supporting a study called SHAPE-PID to better understand how primary immunodeficiencies (PIDs) affect people's daily lives.

The SHAPE-PID study involves a 30-minute online survey to explore the symptoms of PID, how it impacts your quality of life, work or school, emotions and more.

Any patient with a doctor-confirmed PID diagnosis can take part, as well as their caregivers.

If you have a child aged 4 years or older who qualifies, you can also complete a survey on their behalf. If they are 13-17 years old, they can complete the survey themselves as long as you first provide the consent for them to do so.

Why is this research important?

Taking part is voluntary, but by sharing your experiences, you can:

- Help raise awareness of how PID may affect everyday life, including emotional well-being, work, studies and finances.
- Make your voice heard and potentially influence key decision makers in the development of future treatment options for people with PIDs.
- Contribute to research findings that may be presented at scientific conferences and published in a scientific journal.

Is there any risk if I take part?

- Your responses will always remain private and confidential.
- Your individual answers will not be shared with Immunodeficiency UK or IPOPI.
- Taking part will not change the quality of care you receive.

You can take part by first clicking on the link below:

📌 https://survey.euro.confirmit.com/wix/p174440722417.aspx?__userid=OpenUKLive&DLT=4&src=9&C=8&l=9

Join The Great British Step-Off & raise funds for a cause that matters

THE GREAT BRITISH
STEP-OFF

Fan Y Big - 10,000 steps
Pen Yr Helgi Du - 12,000 steps
Pen Y Fan - 12,000 steps
Skiddaw - 13,000 steps
Fan Brycheiniog - 14,000 steps
Tryfan - 14,000 steps
Moel Eilio - 15,000 steps
Blencathra - 15,000 steps
Moel Siabod - 16,000 steps
Cadair Idris - 17,000 steps
Helvellyn - 17,000 steps
Glyder Fach - 18,000 steps
Scafell Pike - 18,000 steps
Ben Lomond - 18,000 steps
Snowdon (Yr Wyddfa) - 20,000 steps
Aonach Mor - 21,000 steps
Carnedd Llewelyn - 21,000 steps
Ben Macdui - 22,000 steps
Snowdon Horseshoe - 26,000 steps
Ben Nevis - 28,000 steps

Ever wondered what it feels like to climb 20 of the UK's most iconic mountains? Now you can – without leaving your local park, pavement, or treadmill!

The Great British Step-Off is a *free*, fun, and flexible virtual challenge where you'll walk the equivalent of 20 mountains in 30 days – that's roughly 11,000 steps per day.

Here’s how it works:

✅ Walk anywhere – your street, local park, or even your treadmill.
✅ Track your steps – with Strava, Garmin, Fitbit, or any app.
✅ Split the mountains – one mountain can be completed over several days.
✅ Raise vital funds – choose *Immunodeficiency UK* as your charity when you sign up and help us support people living with primary and secondary immunodeficiencies.
✅ Celebrate your success – earn a finisher’s certificate when you complete the challenge!

Every step you take helps fund better support, awareness, and brighter futures for those with immunodeficiency.

Ready to make every step count?

1️⃣ Sign up here and select Immunodeficiency UK as your chosen charity.
2️⃣ Set up your fundraising page – we’ve put together a quick guide to help you get started.
3️⃣ Share your page, invite friends, and start stepping!

Please consider turning your daily steps into supporting Immunodeficiency UK.

Join The Challenge Today

Latest advocacy activities

Immunodeficiency UK works to improve healthcare and treatment access for people with immunodeficiency by engaging in consultations, building alliances, and representing the community on key committees, ensuring that patient voices are always heard.

Here are some of the recent advocacy activities we’ve undertaken on behalf of those affected by primary and secondary immunodeficiency.

In August, Immunodeficiency UK made a patient group submission to the Scottish Medicines Consortium (SMC) to ensure the voices of people living with Activated PI3K Delta Syndrome (APDS), their families, and carers are heard in the evaluation of a new treatment, Leniolisib (Joenja). This treatment was approved by NICE (National Institute for Health and Care Excellence) for use in England earlier this year. We also provided feedback to NHS England on the service specification for NHS Genomic Medicine Services.

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