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Welcome to the August Immunodeficiency UK newsletter!



We hope you are keeping safe and well, and enjoying the great British summer!

August's newsletter is brief, as staff take a well-needed break, but you'll still find all this month's important updates below, with more to follow in September.

ReGen-Cov antibody combination prevents Covid-19

The ReGen-Cov antibody combination (casirivimab and imdevimab) has been shown to prevent Covid-19 infection. Results published in the [New England Journal of Medicine](#) showed that ReGen could prevent Covid-19 infection among household contacts of Covid infected individuals.

Immunodeficiency UK pressed the government to speed up access to this therapy for our community. Our CEO, Dr Susan Walsh, was featured in an article in The Times and her letter was also published.



We are delighted that the government has since [approved the first monoclonal antibody treatment](#) for COVID-19 for use in the UK.

Newborn screening for severe combined immunodeficiency – NHS evaluation to start in September

An evaluation of [newborn blood spot screening](#) for severe combined immunodeficiency (SCID) will begin in England on 6 September 2021. The evaluation will help the [UK National Screening Committee](#) to decide whether to recommend including SCID as part of the national newborn screening programme.

SCID affects about 1 in 40,000 babies born in England (about 14 or 15 babies a year). About a third of babies are diagnosed because of a family history and benefit from early, life-saving treatment. It is hoped that early detection of SCID through screening will lead to successful treatment for all children.

The screening evaluation will take place in two-thirds of the country over a two-year period. In the areas taking part, screening for SCID will be offered as part of the existing newborn screening programme. The programme currently offers all babies up to a year of age screening for [nine other conditions](#).

Screening involves collecting some blood from a baby's heel onto a specially designed card when the baby is five days old. Babies with a positive screening result for SCID will be referred immediately to immunology services for diagnostic tests.

As part of the evaluation, the screening programme will ask parents about their experiences of SCID screening. This will help to show whether the potential benefits of SCID screening outweigh any potential harms.

A [new leaflet](#) is available for parents in SCID screening areas. For more information about the evaluation please see the [PHE Screening blog](#).

Immunodeficiency UK September 10k

Back for 2021!

If you were inspired by the olympics, or you're looking for your next challenge, why not take part in our virtual 10k next month?

Complete the distance in one go and aim for a new PB, or go at your own pace throughout the month.

To get involved, email: jen@immunodeficiencyuk.org



Paul shares his story



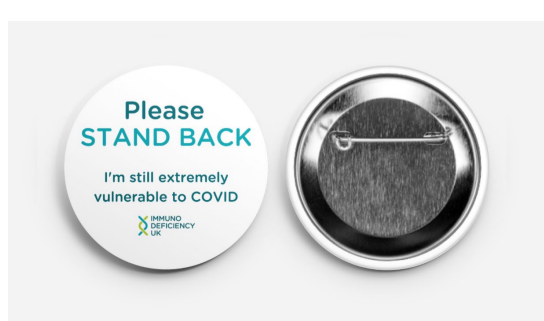
Paul remembers being regularly unwell from the age of seven.

He was eventually diagnosed with hypogammaglobulinemia in his early thirties.

Thank you to Paul for generously sharing his experiences with our community.

[Read Paul's Story](#)

'Please Stand Back' Pin Badges



Let others know you still need space.

To request your free pin badge, please send your name and address to jen.rush@immunodeficiencyuk.org.

Patient survey on use of remote consultations



The aim of the survey was to explore the experiences of remote consultations by members of the immunodeficiency community. Since the start of national restrictions due to the coronavirus pandemic, many consultations have moved from face-to-face to remote (telephone video or online) both in general practice and hospital specialties.

This survey asked members of the Immunodeficiency UK Community for their experiences of remote consultations with their Immunology Teams. The survey ran from 13th May to 7th June 2021 and was made available via social media, Immunodeficiency UK's newsletter, and an emailed member invitation. Immunodeficiency UK would like to thank those who took part.

[View survey findings](#)

Well done and thank you to friends of Paul Ash

We'd like to say a huge well done and thank you to the friends of Paul Ash. They recently completed the Yorkshire Three Peaks Challenge in under 12 hours.



So far the group have raised an incredible £6,375 in memory of their friend 'Pash', who suffered with an immunodeficiency and sadly passed away earlier this year. [Read more on their Just Giving page.](#)

Thank you to our sponsored walkers!

A huge thank you to everyone who took part in our first Sponsored Walk Weekend. Participants chose the length and location of their walks and have so far raised over an incredible £1,500!

Here are Michael and Hanna ready to take part in their walks while sporting their Immunodeficiency UK T shirts:



Supported by an educational grant from Biotest (UK) Ltd



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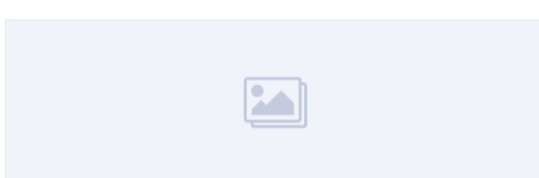
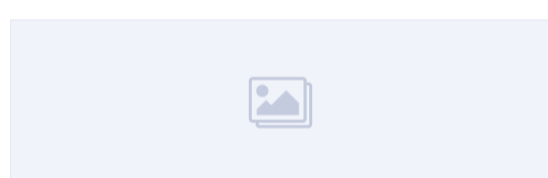
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