



Welcome to the January Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Happy New Year and welcome to the first newsletter of 2024.

We have a lot to update you about in this month's newsletter.

Read on for our monthly news round up and, don't forget to [like us on Facebook](#) to get updates throughout the month.

A huge thankyou

We were overwhelmed with the outpouring of support we received from our incredible supporters during our Giving Tuesday and Christmas fundraising

campaign. Your unwavering commitment to Immunodeficiency UK truly made the season extra special, and we wanted to take a moment to express our deepest thanks.

Your generous donations will go towards providing crucial support and resources to those affected by immunodeficiency.

It's heartwarming to see a community come together to make a positive impact, especially during the holiday season.

As we embark on a new year, we look forward to continuing to support the immunodeficiency community. Together, we can make a lasting difference in the lives of those affected by immunodeficiency.


Once again, thank you for your incredible generosity.

Wishing you a joyful and healthy 2024!

New Year – New Website

The screenshot shows the top of the Immunodeficiency UK website. At the top is a dark teal navigation bar with white text for contact information: "Freephone 0800 987 8986 | hello@immunodeficiencyuk.org". To the right are four green buttons with white text: "DONATE NOW", "MEMBERSHIP", "HEALTHCARE PROFESSIONALS", and "ENGLISH". Below this is a white navigation bar with the Immunodeficiency UK logo on the left and a menu of links: "Immunodeficiency", "Supporting you", "Our Charity", "Resources", "Get involved", "News", "Contact", and a search icon. The main content area features a teal sidebar on the left with the heading "Supporting families affected by primary & secondary immunodeficiency" and a paragraph of text. To the right is a large photograph of a woman and a young girl laughing joyfully outdoors, with a small teal accessibility icon in the bottom right corner of the image.

We're thrilled to share some exciting news with you! Immunodeficiency UK has a brand-new online home, and we can't wait for you to explore it.

 Introducing Our New Website: <https://immunodeficiencyuk.org>

Why visit?

Immerse yourself in a user-friendly space designed with you in mind. Our new website is a hub of information, resources, and support for individuals and families affected by immunodeficiency.

Through our website you can find:

- Medical and practical information
- Latest research and updates
- Patient experience stories
- Information about our advocacy work
- Current and former newsletters
- A library of over 70 downloadable booklets on a variety of topics relevant to the immunodeficiency community.

Visit <https://immunodeficiencyuk.org> today and experience the difference.

Thank you for being a vital part of the Immunodeficiency UK community.

Together, we can empower, educate, and inspire.

Margaret joins the STRAVINSKY patient involvement panel

STRAVINSKY stands for 'Stratification of Clinically Vulnerable People for COVID-19 Risk Using Antibody Testing'. It is a new 2-year study which aims to establish if antibody testing can identify who remains at greatest risk of severe COVID-19 infection after vaccinations.

The STRAVINSKY study will find out if an antibody test result can predict these individuals' risk of severe COVID-19 infection. To do this, up to 2,600 patients, who are clinically vulnerable, will be recruited from all backgrounds to take part. The researchers also want to find out if measuring antibodies is a helpful predictive tool in identifying those individuals most at risk of catching COVID-19. This will help clinicians to provide better clinical care for these patients in the future.

Margaret joined the Patient Involvement Panel (PIP) for the STRAVINSKY trial last year and here she reports on the project and her role.



'My name is Margaret, and I was diagnosed with CVID in 2002. I'm happy to be a participant of this trial that aims to support us as someone directly affected by a primary immunodeficiency.'

I applied to be a PIP member for the STRAVINSKY trial in Autumn last year and my application was successful with the committee meeting for the first-time last November.

As we all know it has been a scary time for us all since COVID-19 struck in 2020. The government hastily took specialist advice to decide who was most at risk of COVID-19. The list included people affected by PID and secondary immunodeficiency and many other groups that the STRAVINSKY study is now looking at, including groups with cancer, autoimmunity, liver and heart disease, bone marrow transplant and many more.

It has been found that there is still a great variation in outcomes within these groups too when they get COVID-19. Some people can get really ill, and might need hospitalisation and others cope much better than expected, but no one knows why. That is what the STRAVINSKY study is hoping to find answers to. To date patients have been recruited across a variety of teaching hospital across the UK. Please have a look online via the [STRAVINSKY study website](#) as you may be able to volunteer too. For most volunteers this involves a finger prick blood test that is posted back to your local centre. The more information gathered will hopefully provide information to inform us on how much protection we are getting from the vaccination programme and from having had a previous COVID-19 infection.

The aims of the PIP are to advise and guide STRAVINSKY researchers through providing honest feedback and reflections on the research priorities as well as perspectives and thoughts on the wider implications of the research for other emerging COVID-19 research and policy. The plan is to meet five times over the two-year period of the study.'

Accessing a COVID-19 vaccination – it's not too late!

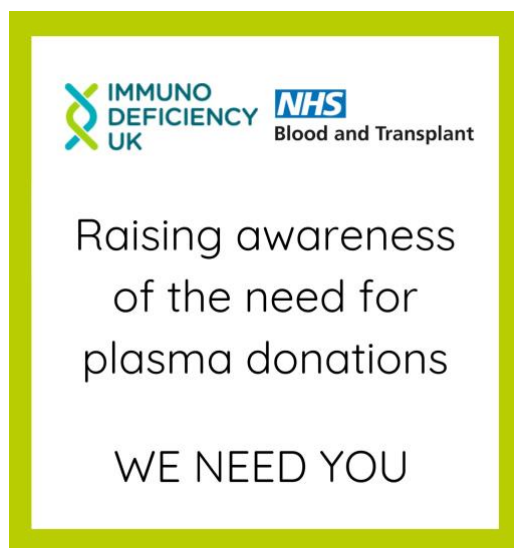
In England, you can no longer book a seasonal COVID-19 vaccine online or by calling NHS 119. You may be able to book a COVID-19 vaccine with a local NHS vaccination service, or you can [find a Covid-19 vaccination walk-in site](#). The booster is available until 31 January, 2024.

In Wales, people who are eligible for a COVID-19 autumn booster should have received an invite. If you are eligible and have not received an invitation, please [contact your local health board](#). The booster will be available until March 31, 2024.

In Scotland, people who are eligible for a COVID-19 autumn booster can [book online](#), call 0800 030 8013 or visit a [drop in clinic](#). The booster will be available until March 31, 2024.

In Northern Ireland, the COVID-19 autumn booster may be available via your GP or a local pharmacy. Check [here](#) for more details.

We need you!



We are pleased to announce that Immunodeficiency UK will be partnering with NHS Blood & Transplant (NHSBT) to hold an event in the Houses of Parliament on Wednesday, the 20th March, to increase awareness of the need for plasma donations. Plasma is needed to make immunoglobulin (IG) and more people are needed to come forward to donate.

The event is also an opportunity to raise awareness of primary and secondary immunodeficiency. Immunodeficiency UK will be contributing towards the costs of holding the event, with NHSBT covering the majority part.

We need your help!

Contact your MP – March 2024 Parliamentary Event

We need YOU to write to your local MP to encourage them to attend the event, make them aware of the need for plasma donation and make them aware of primary and secondary immunodeficiency. Please email your MP – we've drafted an email you can use to tell them about the event. Just [click here](#). MPs will have already received 'a save the date' invitation from NHSBT but receiving emails from local constituents are likely to carry more weight. You can find contact details of your MP using this link [Find your MP - MPs and Lords - UK Parliament](#).

Tell your story in person at the event!

We are also looking for up for people to come forward to attend the event in person and tell their story of what difference having immunoglobulin therapy makes to them or their children. Please do get in touch with us at hello@immunodeficiencyuk.org if you are interested in helping, stating the

condition for which you receive IG therapy, where you live and we will let you know more details. We want to attract people from diverse backgrounds, affected by different immunodeficiency conditions, and would be delighted to hear from parents of young children who are dependent on IG therapy to keep their children well.

Changes in Northern Ireland and Wales on how to report a positive COVID-19 test



From January 2024, **Northern Ireland** has changed how to report a COVID-19 rapid lateral flow test for those who are eligible for COVID-19 treatments.

From January 2024, you should report your positive lateral flow result on line at the [NI Direct Coronavirus \(COVID-19\): testing and stay at home advice](#) webpage – see the section ‘Reporting your lateral flow test results’.

For those people who are not able to report their test result online, advice will be provided to contact their GP or GP Out of Hours who can contact the Trust on their behalf. [The NI Direct Treatment for Coronavirus \(COVID-19\) webpage](#) will continue to be kept up to date with information on COVID-19 treatments, including links to the updated testing information and how to access COVID medicines.

In Wales

From the 1st February, eligible individuals in the community will no longer be able to order LFTs online via the [Gov.uk order](#) lateral flow tests portal. Instead, tests should be collected from participating pharmacies. You will be [able to search for participating pharmacies here](#).

There will also be a change to how you report your positive COVID-19 result. Positive results should be reported directly via the [online self-referral portal](#) or for people who cannot access the online portal, by calling NHS111. Once completed, the relevant health board’s antiviral service will make contact as per current processes. This will usually be within 48 hours, but may take longer at weekends and bank holidays. Treatment will be arranged if appropriate.

You find information on how to access COVID-19 treatments and LFTs in all four home nations at [Access to COVID-19 treatments - Immunodeficiency UK](#).

Accessing free LFTs in Scotland and England

In Scotland

You can no longer use the Gov.uk portal. NHS Scotland has now set up a new online service for eligible people to order free rapid lateral flow tests [Lateral flow test login - Lateral Flow Test Portal \(service-now.com\)](#).

You will need to register an account online via the link above to access this service for the first time.

If you're eligible for free NHS tests and you cannot place an order online, phone 0800 008 6587.

Update on access to free LFTs via pharmacies in England

According to information from NHS England, many pharmacies have recently updated their profiles on the NHS England website to indicate whether they offer lateral flow tests.

To find a pharmacy near you, please use the 'Find a pharmacy' link (<https://www.nhs.uk/service-search/pharmacy/find-a-pharmacy>), enter your postcode, click on each pharmacy, and navigate to the 'Treatments and services' section under the overview. Scroll down to check if 'COVID-19 lateral flow tests (eligible NHS patients)' is listed under 'Screening and test services.'

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team