



December
Newsletter

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Welcome to the December Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member, we hope you are keeping safe and well and looking forward to Christmas.

Read on for our monthly news round up and, as always, please don't hesitate to get in touch if you have any questions or comments.

Share your views with the UK enquiry into the forgotten500k

An enquiry has begun to look at what lessons can be learnt from the UK's handling of COVID-19, and how it has affected people with health conditions that affect their immune system. Five key areas will be assessed as part of the UK enquiry, including i) availability and access of pharmaceutical products, ii) decision making, iii) research, iv) communication with stakeholders including patients and clinicians v) digital and data.

To provide your own input and experiences, please respond to the survey [here](#). **The inquiry will collect evidence until the end of working day on the 17th of January 2023 so please submit before then.** This is a good opportunity to get your opinion heard.

The enquiry report will be published by the All-Party Parliamentary Groups (APPG) for Vulnerable Groups to Pandemics co-chaired by Bob Blackman MP and Lord Mendelsohn and shared with MPs across both the House of Commons and the House of Lords. More information can be found on the link below.

[More info→](#)

Accessing care, living with COVID-19, and enjoying Christmas



Christmas is nearly here! It is important you know how to access care over the holiday period. People with ongoing active health problems should have a plan from their clinician for accessing care over the longer bank holidays.

This may include specific advice in case of worsening health and what the threshold of concern should be in certain circumstances, and who to contact. If you have back up antibiotics you should be given guidance about when to start them again and under what circumstances.

Plan ahead - think about medicines you might need and make sure you have an adequate supply. Your GP should always be first port of call and your immunology centres should have out of hours contact information. In an emergency call 999, if you are unwell but not critical, and need advice, call NHS 111. If you are not sure call 999, and they will triage.

The mechanism of access to COVID-19 medicines over the Christmas period remains the same and there is currently no change to the range of therapies available. Please do familiarise yourself with what to do if you should test positive for COVID-19 by reading our [information sheet here](#).

Be COVID-19 aware in social settings. Everyone deals with the risk posed by COVID-19 in their own way, but don't go out of your own comfort zone just to please others. For gatherings at home consider asking friends and family to have COVID-19 tests, keep your rooms ventilated and avoid shared food such as dips. Following the 'Hands, Face, Space' motto remains a good thing to do to reduce the risk of contracting COVID-19.

Looking after your mental health at Christmas



Whilst Christmas is thought of as the season to be merry and bright, it can also be a time of loneliness and feelings of being over-whelmed to live up to the huge pressure to have a 'good time'. Many people do find Christmas difficult, so, do look after your mental wellbeing.

If you are spending Christmas alone, have a think about what you want to do beforehand and plan the day doing things that you most enjoy. Just be gentle and easy with yourself. If you are worried, sad, or simply overwhelmed, under pressure about Christmas, don't be afraid to talk to someone about it. Have a chat to someone you trust. Read some useful articles from the mental health charity MIND on how to cope at Christmas. [Christmas coping tips - Mind](#)

Welcome Tamara and Patricia

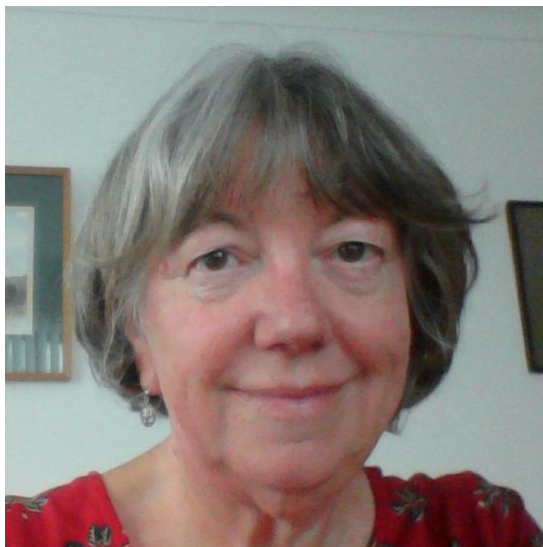
We recently added two new additions to the Immunodeficiency UK team, Tamara Moubazbaz who joins us as our newest trustee and Patricia Hamilton who joins the patient representative panel.



Tamara was diagnosed with a primary immunodeficiency in 2013, after a decade of poor health and miserable quality of life. In her day job as a market researcher, she helps brands grow and hopes that she can apply her skills to contribute positively to Immunodeficiency UK.

Tamara says: "The pandemic years have made me realise just how little is understood by the general public about the immune system and have prompted my desire to get involved in whatever way I can."

Find out more about Tamara and our other our trustees at <http://www.immunodeficiencyuk.org/aboutus/ourtrustees>



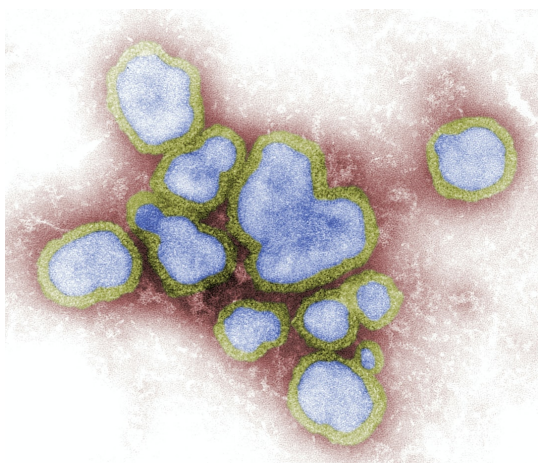
Patricia lives in Greater Manchester and brings with her a wealth of medical knowledge as she was a GP for 27 years. Her son was diagnosed with CVID as a teenager and she was subsequently found to have IgA deficiency, so she knows first-hand the challenges that people living with an immunodeficiency face.

Patricia says: "I am happy to offer support to others affected by immunodeficiencies through this wonderful organisation. I am especially keen to continue to support Immunodeficiency UK to raise awareness of immune deficiencies among patients, health professionals and the public at large."

Find out more about our Patricia and the rest of our patient representative panel at <http://www.immunodeficiencyuk.org/aboutus/patientrepresentativepanel>

Welcome Tamara and Patricia, we are excited to have you on board and look forward to working together to support people living with an immunodeficiency and their families.

Flu and access to anti-virals



Cases of Flu are on the increase and antivirals for the prophylaxis and treatment of flu can now be prescribed for clinical at-risk groups or in anyone at risk of severe illness or complications from influenza. It can be difficult to distinguish between the symptoms of COVID-19 and flu so for people who have a significant immune deficiency it may be worth considering buying a lateral flow test for flu (cost between £1 - £2).

People with a positive Flu A/B test can access antivirals (oseltamivir or zanamivir) via their GP or their specialist centre. People with PID/SID who have

had a known household contact but are currently asymptomatic may also be eligible. For people with existing co-morbidities such as diabetes, COPD, bronchiectasis and heart disease accessing treatment is recommended and must start ideally within 48 hours of symptoms to be useful.



Thank you so much for all your support on **Giving Tuesday** which took place on November 29th. We were overwhelmed by your generous spirit and your donations will help us be there for people affected by immunodeficiency. Thanks to everyone who donated, engaged with us on [Facebook](#) or shared our campaign. We are truly grateful and you helped us raise £100s of pounds in just one day.

We are lucky to have some really amazing supporters here at Immunodeficiency UK and your support over the whole of 2022 is so appreciated. We receive no public funding so your generosity helps to support us to deliver a range of services. To everyone who fundraised, donated, shared our campaigns, volunteered time or engaged with us on our social channels, WE THANK YOU. We truly couldn't do it without you.

If you'd like to fundraise for us in 2023 [please get in touch](#). We are here to support you.

Xmas closures

The Immunodeficiency UK office will be closed for the festive period from the 23rd December to the 3rd January.

If you need to seek medical help, then contact NHS 111, by phone or via the [NHS 111 website](#), if you have an urgent medical problem or if you are not sure what to do. Please note the 999 service should only be used for life-threatening emergencies.

We hope you all have a wonderful Christmas and New Year, and we'll see you in 2023.

Have a lovely Christmas and New Year,
Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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