

December Newsletter

Welcome to the December Immunodeficiency UK newsletter!



Welcome to the December newsletter. We hope you find the information useful to you.

Read on for our monthly news round up and, don't forget to visit us on Facebook to get updates throughout the month.

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

Meet Clare Brailsford: Our New Trustee



We are thrilled to introduce Clare Brailsford as one of our new trustees. Clare brings a wealth of personal and professional experience to our board, as well as a deep understanding of the challenges faced by those with immunodeficiency.

Clare's journey with immunodeficiency began when her daughter was diagnosed with Common Variable Immunodeficiency (CVID) at the age of 7.

Over the years, she has supported her daughter through various treatments, including subcutaneous immunoglobulin replacement therapy and later transitioning to IV infusions at the Royal Free Hospital as she moved into adult services.

While Clare was familiar with Immunodeficiency UK before the pandemic, it was during the shielding period of COVID-19 that she truly engaged with the charity. She appreciated the support, advice, and community that Immunodeficiency UK provided, and this connection inspired her to become more involved.

As a retired librarian, Clare brings many years of experience in information dissemination, which she plans to leverage in her role as trustee. She is passionate about ensuring that families facing immunodeficiency have access to reliable information and the support they need.

In addition to her role with Immunodeficiency UK, Clare is actively involved in her local community, volunteering at her local library and serving as a governor at a primary school in St Albans.

We are excited to have Clare on board and look forward to the invaluable contributions she will make to our work and mission.

Your Support Can Transform Lives This Christmas

Make a real difference THIS CHRISTMAS

As we approach the festive season, we at Immunodeficiency UK are reflecting on the incredible impact your support has made. Thanks to your generosity, we've been able to:

- · Support over 260 individuals through our helpline
- Distribute 4,150 educational booklets
- Facilitate regular mental health support groups
- Provide crucial hardship grants to those in need

But there's still more to be done. This Christmas, we're asking for your help to continue our vital work.

Did you know that £30 funds an hour of support via our helpline? That's an hour of comfort, information, and reassurance for someone grappling with immunodeficiency.

Your donation, no matter the size, can make a significant difference:

• £5 helps print and mail an informational booklet

- £10 contributes to a child-friendly Medikidz comic book about PID
- £50 provides a Buzzy Shot pain relief device for a child's treatment
- £100 funds a hardship grant for additional expenses

"It was a massive help to receive the grant as I was able to put the money towards travelling for treatment." - Grant recipient

This Christmas, give the gift of support. Together, we can ensure no one faces immunodeficiency alone.

Donate Now

Thank you for any donation you can make.

Accessing care 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. If you are unwell but not critical, and need advice, call NHS 111. Only use the 999 service for life-threatening emergencies.

The mechanism of access to COVID-19 medicines over the Christmas period remains the same. Please do familiarise yourself with what to do if you should test positive for COVID-19 by reading our website information.

Looking after your mental health at Christmas

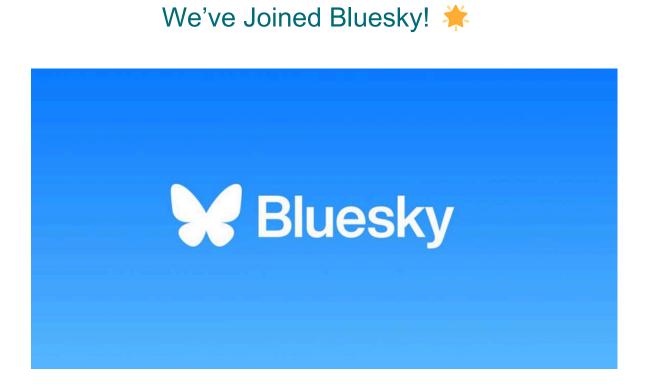
Whilst Christmas is thought of as the season to be merry and bright, it can also be a time of loneliness and feelings of being over-whelmed to live up to the huge pressure to have a 'good time' especially in this era of social media. Many people do find Christmas difficult, so, do look after your mental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

The mental health charity MIND has an excellent article on how to cope at Christmas. It may help normalise some of the feelings you are experiencing.

Do you receive IG Therapy?



If you currently receive immunoglobulin (IG) and want to help with campaigns, NHS Blood and Transplant would like to hear from you. NHSBT is planning more plasma donation campaigns next year to mark the arrival of immunoglobulin made from UK plasma. To find out more, email Stephen.bailey@nhsbt.nhs.uk



Exciting news! Immunodeficiency UK is now on Bluesky, a new and growing social media platform.

By joining Bluesky, we're expanding our digital presence to connect with even more of our community, share vital information, and raise awareness about immunodeficiency. Whether it's updates, support, or advocacy news, we'll be there engaging in meaningful discussions.

Follow us on Bluesky to stay informed and connected.

Find us on Bluesky: https://bsky.app/profile/immunodeficiencyuk.bsky.social

Xmas closures

The Immunodeficiency UK office will be closed for the festive period from the 24th December to the 2nd 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.

Help Us Be 1 of 120 Charities to Win £1,000!



This holiday season, we're taking part in the **12 Days of Giving** by the Benefact Group, where **120 charities** will each receive a **£1,000** donation. This incredible opportunity could help us continue our vital work, but we need your help! Nominate our charity today and give us the chance to be one of the lucky 120 charities. Every nomination counts!

Nominations are open until **December 19, 2024**, and it only takes a minute to make a difference.

Click here to nominate us now!

We hope you all have a wonderful Christmas and New Year, and we'll see you in 2025.

Best wishes, Susan and Fay The Immunodeficiency UK Team