

December Newsletter

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Welcome to the December Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

The festive season is almost upon us and we hope that you're looking forward to Christmas.

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 <u>like us on Facebook</u> to get updates throughout the month.

Rare Minds





Supporting families affected by primary and secondary immunodeficiency

Mindfulness for Pain, Fatigue and Anxiety

A 1.5 hour taster session (Zoom)

Thursday 18th January 6pm - 7.30pm

This session offers the opportunity to find out more about what Mindfulness is (and isn't) and it's growing evidence base* for addressing pain and fatigue. There will be opportunities to ask questions, try some exercises, and learn more about the upcoming 8 week course.



Steve Smith (Session Facilitator) works with Avon Valley NHS Primary Care delivering Mindfulness Based interventions for patients living with stress, anxiety and chronic pain. He has been teaching Mindfulness for over 10 years, is Mindfulness Lead for Rareminds and a Trainer/Supervisor with a leading UK Mindfulness Training Provider. He is passionate about the benefits of Mindfulness as a practical tool for everyday living.

To book your place, please contact Steve on steve@rareminds.org

*Mindfulness based techniques are increasingly being used in the NHS for a range of chronic conditions, including pain and low mood. Further information about Mindfulness can be found at:

https://www.nhs.uk/mental-health/self-help/tips-and-support/mindfulness



Immunodeficiency UK is dedicated to providing valuable support to people with immunodeficiency and we are excited to announce a collaboration between Immunodeficiency UK and Rare Minds, to bring you a series of webinars designed to improve your mental health and enhance your well-being. Our first webinar, "Mindfulness for Pain, Fatigue, and Anxiety," will take place on January 18th (details below). This webinar is a taster session in preparation for their 8week course which you can sign up for free of charge following this webinar.

Event Details:

- Date: January 18th
- Time: 6:00 PM 7:30 PM

- Where: Zoom

What to Expect:

Find out more about what Mindfulness is (and isn't) and its growing evidence base for addressing pain and fatigue. There will be opportunities to ask questions, try some exercises, and learn more about the upcoming 8-week course.

Why Attend?

- Gain a deeper understanding of mindfulness techniques
- Learn practical strategies for managing pain, fatigue, and anxiety
- Connect with a supportive community facing similar challenges
- Access valuable resources to enhance your daily life

How to Register:

To book your place, please contact Steve on <u>steve@rareminds.org</u>. Don't miss this opportunity to embark on a journey of self-discovery and empowerment!

We hope you'll attend this transformative event!

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.

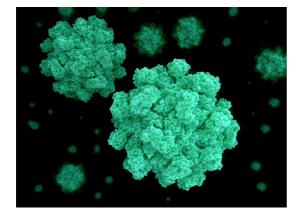
Plan ahead - think about medicines you might need and make sure you have an adequate supply. Your GP should always be first port of call and your immunology centres should have out of hours contact information. If you are unwell but not critical, and need advice, call NHS 111. Only use the 999 service for life-threatening emergencies.

The mechanism of access to COVID-19 medicines and lateral flow tests 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 <u>website</u> information.

Be COVID-19 aware in social settings. Everyone deals with the risk posed by COVID-19, and other respiratory viruses, in their own way, but don't go out of

your own comfort zone just to please others. Avoid people who are ill. For gatherings at home, you might consider asking friends and family to have COVID-19 tests, keep your rooms ventilated and avoid shared food such as dips.

Norovirus and immunodeficiency



Norovirus is a common infection that causes diarrhoea and vomiting. It is often referred to as the 'winter vomiting bug' and we have been hearing a lot about an uptick in norovirus infections in the news.

Most people infected by norovirus recover within a day or two but symptoms frequently last up to five days. In the young, elderly or people with weakened immune systems, norovirus can last longer, and it is easy to get dehydrated, so it is important to drink plenty of fluids to prevent this.

Norovirus is highly contagious and is easily passed from person to person as it is transmitted by touching hands or surfaces that the virus has landed on. One of the best ways to protect against norovirus and to help prevent infection is by practising good hygiene. This includes thorough hand washing with soap and warm water, especially after using the toilet and before eating or preparing food. Please note that alcohol-based gel alone probably won't kill norovirus, so it is best to use soap and water.

You can read more information about norovirus <u>here</u>, including how it may affect some people with immunodeficiency.

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 about £3 from a well-known high-street pharmacy store).

People with a positive Flu A/B test can access antivirals (oseltamivir or zanamivir) via their GP or their specialist centre. People with primary or secondary immunodeficiency 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.

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 <u>how to cope at</u> <u>Christmas</u>. It may help normalise some of the feelings you are experiencing.

Join Team Immunodeficiency UK at the London Landmarks Half Marathon 2024!



At Immunodeficiency UK, we are excited to announce a thrilling opportunity for our sporty supporters to lace up their running shoes and join us in the London Landmarks Half Marathon 2024!

We only have 2 places left so sign up now.

As a valued member of our community, your commitment to our cause has made a significant impact, and now we invite you to take the next step – quite literally – by becoming a part of Team Immunodeficiency UK in one of the most iconic running events in the world.

By participating in the London Landmarks Half Marathon, you'll not only be challenging yourself physically and mentally but also helping raise crucial funds to support individuals and families affected by immunodeficiency. Every step you take will contribute to our mission of improving lives, providing essential resources, and raising awareness.

What's in It for you?

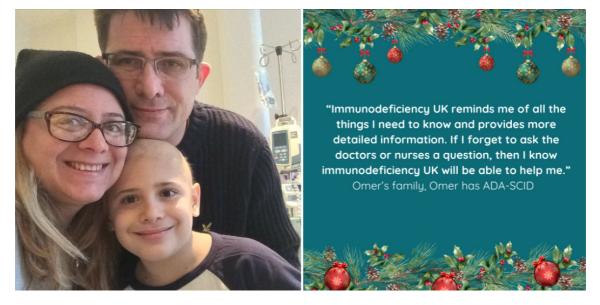
- Join a supportive and enthusiastic community of like-minded individuals, all running for a common cause.
- Receive a branded running top to proudly showcase your commitment on race day.
- Your dedication will be celebrated through our social media channels and newsletters, acknowledging your vital role in making a difference.

How to sign up

- 1. Secure your spot in the London Landmarks Half Marathon by emailing <u>fay.fagon@immunodeficiencyuk.org</u>
- 1. Commit to raising a minimum of £500.
- 1. Kickstart your fundraising journey by setting up a personal fundraising page on <u>JustGiving</u>. Share your story, and watch as your friends, family, and colleagues rally behind you.

Save the Date London Landmarks Half Marathon 2024 Date: 7 April 2024 Location: London

Embark on this incredible journey with us, and together, let's make every stride count. Your determination will go a long way in supporting those who need it most.



Will you set up a monthly gift?

"Immunodeficiency UK reminds me of all the things I need to know and provides more detailed information. If I forget to ask the doctors or nurses a question, then I know Immunodeficiency UK will be able to help me," said Omer's family, Omer has Adenosine deaminase (ADA) SCID deficiency (ADA-SCID). an inherited disorder where catching infections that can be very serious or life-threatening.

Families like Omer's rely on Immunodeficiency UK to access vital resources and support. A monthly donation of just £10 could help ensure we can be there for

families affected by immunodeficiency. Will you commit to providing ongoing support this Christmas?

Fundraise for Immunodeficiency UK at no cost to you



You can turn your last-minute Christmas or grocery shopping into big donations for Immunodeficiency UK when you use Easy Fundraising. They've even put together all the latest donations and offers from your favourite supermarkets in one place! Find out more at <u>https://www.easyfundraising.org.uk/grocery-hub</u>

Need a last-minute Christmas card?



This year you can spread cheer and support Immunodeficiency UK with our festive E-Cards! Please make a small donation and get access to our e-cards. It is better for the environment than paper and is quick and easy to send. https://www.dontsendmeacard.com/ecards/charities/immunodeficiency-uk

Xmas closures

The Immunodeficiency UK office will be closed for the festive period from the 22nd 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. 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 2024.

Best Wishes, Susan and Fay The Immunodeficiency UK Team



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