



June Newsletter

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Welcome to the June Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the June 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.

It's not too late to get your Spring COVID-19 booster



The poster features a dark blue background with a light blue leaf pattern. At the top left is the UK Health Security Agency logo, and at the top right is the NHS logo. The main headline is in large white text. Below it, a green horizontal band contains text about immunosuppressed individuals. At the bottom, a white rounded rectangle contains the URL for booking.

UK Health Security Agency

NHS

Top up your protection this spring

Those who are immunosuppressed might be eligible for the **spring COVID-19 vaccine offer**

Find out if you're eligible and book online at nhs.uk/get-vaccine

The booster programme will run until the 30 June 2024 in all four home nations so book yours if you haven't yet the vaccination.

In England: You can book your booster via the [National Booking System](#).

In Scotland: NHS Scotland has [information on how to book your booster](#).

In Wales: The booster programme will run until 30 June 2024. NHS Wales will contact you to let you know when and where to have the vaccine. More information can be found at [COVID-19 vaccination information - Public Health Wales \(nhs.wales\)](#).

In Northern Ireland: You can [book your vaccination online](#) or [with a local pharmacy](#).

Green light for impact of PID and SID on psychological health study



As joint project lead, Dr Mari Campbell, Consultant Clinical Psychologist at the Royal Free London NHS Foundation Trust, gives us an update on the progress of this important study to help understand the mental health burden of having a primary or secondary immunodeficiency.

Researchers at the Royal Free London and North Bristol NHS Trusts, with colleagues across the UK, have organised a study to investigate the impact of having a diagnosis of primary or secondary immunodeficiency on psychological health for patients in the United Kingdom. Currently, there is a lack of research into the quality of life and mental health of people diagnosed with an immunodeficiency, and it is hoped that the results of this study will help us to understand patient need in these areas, which is important for informing patient-centred care, policy development and decision making.

The study is called IDIDPsych and is being helped by a grant award from Immunodeficiency UK. Seven Immunology Centres are taking part (Royal Free London NHS Foundation Trust, North Bristol NHS Trust, Heartlands Hospital NHS Foundation Trust, University Hospitals Plymouth NHS Trust, Barts Health NHS Trust, Cardiff & Vale University Hospital Board, Belfast Health and Social Care Trust and NHS Lothian). All patients from these centers who are aged over 16 and have a diagnosis of a confirmed primary or secondary immunodeficiency will be invited to participate in the study. Currently, Royal Free, Cardiff and Barts have the green light to start approaching patients to see if they would like to take part and we hope the other sites will be up and running soon.

Patients who are keen to take part are asked to fill in an online consent form and questionnaire. The questionnaire will use validated measures to assess quality of life, anxiety, depression, fatigue and insomnia, as well as asking about physical health.

Dr Campbell says 'Thank you to those who have taken part to date. We look forward to feeding back the results of this study to you in due course'.

💪 Get involved with your workplace and raise funds for Immunodeficiency UK!



Immunodeficiency UK is dedicated to providing support and invaluable resources to those impacted by primary and secondary immunodeficiency.

But we need your help. Will you consider fundraising in your workplace to help us to continue to provide much needed services to the immunodeficiency community?

Fundraising in your workplace can be a lot of fun and we have some exciting fundraising ideas to get you started:

- Bake Sale or Office Potluck
- Game Tournaments (video games, board games, etc.)
- Fitness Challenges (steps competition, exercise classes, etc.)
- Casual Dress Day or Themed Outfit Contests
- Talent Shows or Open Mic Nights
- Raffles or Auctions

Every contribution, no matter how small, plays a vital role in our mission to enhance the quality of life for the immunodeficiency community. Together, we

can make a lasting difference. Discover how you can get involved at <https://www.immunodeficiencyuk.org/get-involved/fundraising/rally-your-workplace-for-immunodeficiency-uk/>

Show Your Support with Immunodeficiency UK Merchandise



Whether you're living with an immunodeficiency or supporting a loved one, you can proudly raise awareness with Immunodeficiency UK's.

Our [online shop](#) offers a range of stylish and practical items that allow you to showcase your commitment to our cause.

Pin Badges: Elevate your everyday outfits with our eye-catching pin badges. These vibrant accessories are the perfect way to start conversations and spread awareness about immunodeficiencies.

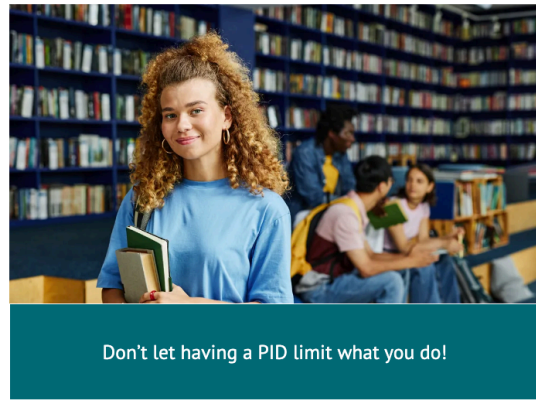
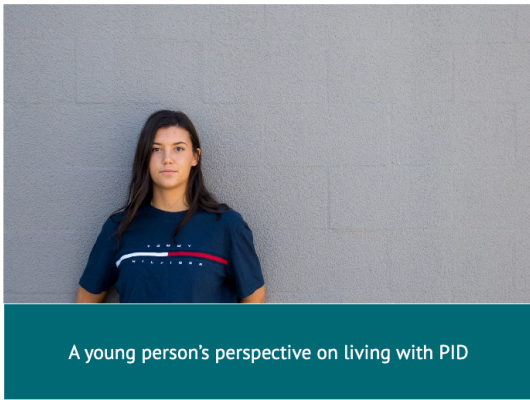
Radar Keys: Unlock accessibility with our handy Radar Keys. These innovative keys provide access to over 9,000 locked disabled toilets across the UK, ensuring convenience and dignity for those with immunodeficiency-related challenges.

T-Shirts: Make a bold statement with our high-quality t-shirts, featuring the Immunodeficiency UK logo. These comfortable and stylish shirts are available in various sizes, making it easy to find the perfect fit.

Running Vests: For those who love staying active, our running vests are a must-have. Designed for optimal breathability and visibility, these vests will keep you comfortable during your outdoor adventures while promoting our mission.

By purchasing from our shop, you're not only expressing your support but also contributing to our ongoing efforts to improve the lives of those affected by immunodeficiency. Explore our collection today and wear your support with pride! Visit <https://www.immunodeficiencyuk.org/get-involved/shop/> to shop now and join our community of advocates.

Immunodeficiency UK's resources for Children and Young People



Children and young people affected by an immunodeficiency may have countless questions swirling in their mind – questions they might feel embarrassed to ask or simply don't know who to turn to.

At Immunodeficiency UK, we're here to provide them with the guidance and support they need on this journey. Our dedicated resources are designed to address their unique concerns and empower them to navigate life with an immunodeficiency.

Whether it's a burning question or a nagging curiosity, we're here to provide them with the information they seek. Our resources include:

A Young Person's Perspective: Gain insight into what it's like to live with an immunodeficiency through the eyes of someone who's been there. Our "A Young Person's Perspective on Living with PID" resource offers a relatable and inspiring look at navigating life with immunodeficiency.

Embracing Their Potential: Having an immunodeficiency doesn't have to limit dreams or aspirations. Our "Don't Let Having a PID Limit What You Do!" resource is packed with practical tips and inspiring stories to help young people live life to the fullest.

Victoria's Story: Follow the journey of Victoria, a young person living with an immunodeficiency. Her story offers a powerful reminder of resilience,

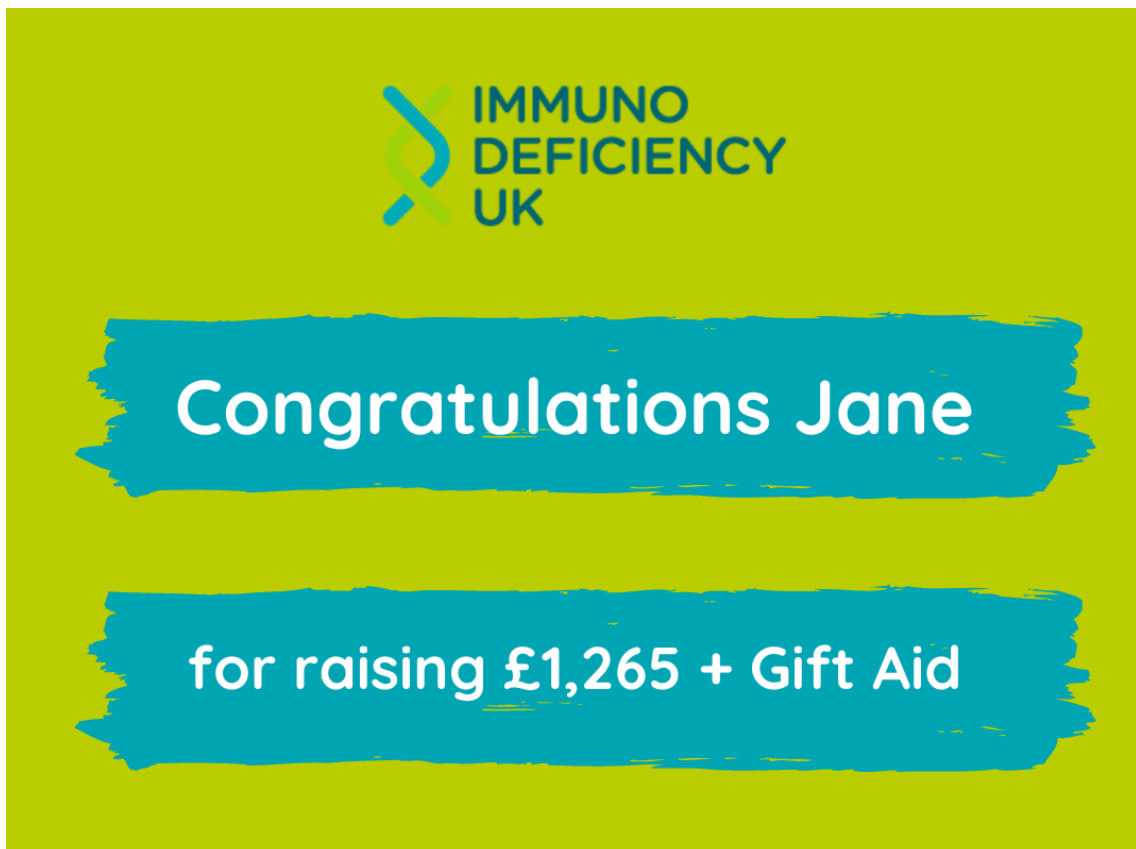
perseverance, and the importance of self-advocacy.

Medikidz Explain Primary Immunodeficiency: Join the Medikidz crew on an engaging and educational adventure as they explore the world of primary immunodeficiency disorders in a way that's easily understandable for young minds.

Our Immune System – A Story for Children with PID: For our youngest readers, this delightful storybook offers a simple and engaging introduction to the immune system and what it means to have an immunodeficiency disorder.

Wherever they are on your journey, Immunodeficiency UK is here to support them every step of the way. Share our resources with a child or young person with immunodeficiency today and help them take charge of their well-being.

Jane's fundraising success



Jane, a full-time working mother of three energetic young boys, has recently accomplished an impressive feat – completing a full marathon and raising £1,265 (plus Gift Aid) for Immunodeficiency UK.

With the unwavering support of her husband, Lee, who avidly encourages her fundraising ventures, Jane decided to take on the challenge of running a

marathon, something she had long aspired to but never mustered the courage to pursue. Inspired by her sister-in-law and a colleague who completed marathons the previous year, Jane finally took the plunge and signed up for the daunting 26.2-mile race. Her motivation stemmed from a deeply personal connection to Immunodeficiency UK, a charity close to her heart.

Tragically, Jane's older brother, Alan, passed away at the tender age of 10 due to an autoimmune disease. Had he survived, he would have been 44 years old today. Running the marathon in Alan's memory and determined to prove that with perseverance, one can achieve their goals, Jane diligently followed a marathon training plan, fueled by her determination and pride. Despite the overwhelming nerves, Jane crossed the finish line, her achievement serving as a testament to her resilience and commitment to the cause. Her incredible achievement has raised vital funds and awareness for Immunodeficiency UK, THANK YOU JANE.

A Heartfelt Thank You for Your Overwhelming Support



At Immunodeficiency UK, we are very grateful for the incredible generosity and dedication of our donors and fundraisers.

Your contributions, no matter their size, have a big impact on the lives of individuals and families navigating the challenges of immunodeficiency.

Together, we can continue to make a lasting difference, one step at a time.

From the bottom of our hearts, thank you.

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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