IMMUNO
DEFICIENCY
UK

# Welcome to the September Immunodeficiency UK newsletter!

Hello Immunodeficiency UK member,

Welcome to the September 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.*

# Transform Childhood Bone Marrow Transplantation!

HAVE YOU BEEN AFFECTED BY CHILDHOOD STEM CELL TRANSPLANTATION?

Guide future research to improve the lives of kids undergoing a transplant

Complete this short 10 minute survey

Contact: jlapsp.bmt@mcri.edu.au

murdoch children's research institute

James Lind Alliance
Priority Setting Partnerships

Immunodeficiency UK are proudly supporting an exciting new international project lead by Murdoch Children's Research Institute, 'Bone Marrow Transplantation (BMT) in Paediatrics Priority partnership. This project is designed to guide future research and innovation in childhood BMT. But your input is vital for this project's success. Murdoch Children's Research Institute is leading the bone marrow transplantation in paediatrics priority partnership, working across Australia, New Zealand, United Kingdom and the Netherlands. The project will steer childhood BMT research in directions that matter most to the entire international BMT community.

The project aims to discover the top 10 research priorities in childhood BMT, and we need your voice.  This will help ensure that those who fund health research are aware of what really matters to patients, caregivers, and health care workers. This project is the first time that adolescents and young adults and children living with conditions requiring a bone marrow transplantation for curative therapy, their caregivers, and health professionals are working in partnership to determine future research goals.

To find out more and get involved you can complete the 10 minute survey at Bone Marrow Transplantation in Paediatrics Priority Partnership - Murdoch Children's Research Institute (mcri.edu.au). Please share your ideas and help make a difference to the lives of children undergoing BMT.

# Help Raise Funds for Immunodeficiency UK: Request Your Collection Box Today!

As we continue our mission to support those affected by immunodeficiency, we want to remind you of a simple yet powerful way you can contribute to our cause.

Did you know that as a member, you can request collection boxes to help raise funds for Immunodeficiency UK? These boxes are a fantastic way to gather donations from your local community, workplace, or events.

1. **Increase Awareness**: Each box helps spread the word aboutimmunodeficiency and our charity.

2. **Easy Fundraising**: They provide an accessible way for people to donatesmall amounts that add up.

3. **Community Engagement**: Placing boxes in local businesses helps buildconnections and support networks.

**How to Request Your Box**

Requesting a collection box is simple:

Just email us at hello@immunodeficiencyuk.org

**Where to Place Your Collection Box** Consider

placing your box in:

- Local shops and cafes
- Your workplace reception area
- Community centres or libraries
- Gym or sports club reception desks
- School or university common areas (with permission).

Every Penny Counts - remember, small donations add up!

## A huge thank you to Shauna

We are overjoyed to share that our dear supporter, Shauna, has completed an exhilarating skydive to raise money for Immunodeficiency UK in honour of her nephew, Oliver Lander.

Shauna's bravery and dedication to this important cause is truly inspiring. Oliver has been dealing with the challenges of APDS, an immunodeficiency that weakens his immune system. This has led to the development of a chronic lung condition called bronchiectasis, requiring a rigorous daily treatment regimen of nebulizers, chest percussion, and prophylactic antibiotics.

Despite these obstacles, Oliver remains a true fighter. In recognition of his resilience, Shauna decided to take on the thrilling feat of skydiving to show her love and support. We are overwhelmed that Shauna's skydive has raised an incredible £1,000 for Immunodeficiency UK.

These crucial funds will go towards supporting families like Oliver's who are navigating immunodeficiency diseases.

On behalf of the entire Immunodeficiency UK community, we extend our heartfelt gratitude to Shauna for her selfless act of bravery. Your jump has not only been an adrenaline-filled adventure, but a true testament to the power of love and community in the face of adversity.

To everyone who has donated to Shauna's fundraiser, we thank you from the bottom of our hearts. Your generosity will make a meaningful difference in the in lives of individuals like Oliver who courageously face unique health challenges every day.

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## It's not too late to join our Mindfulness course

# Mindfulness
# for
# Pain, Fatigue and Anxiety

## An 8 week programme for those living with primary and secondary immunodeficiency

This interactive course just for primary and secondary immunodeficiency patients will be delivered via Zoom in a friendly, supportive group environment with a maximum of 15 participants. It involves in-depth and personalised teaching on the practice and techniques of mindfulness including taught aspects, discussions, exercises, and support for your own practice.

**Weekly on a Thursday, 10th October - 28th November 2024**

**Time:** 7.00pm - 9.00pm

*Nb You will need to allow about 20 minutes per day to practice, and also purchase Course Handbook via Amazon/other online retailer (£10)*

***"The skills I've learnt are already making a difference to the quality of my life. They have helped me to see another way of living with my condition; a calmer, kinder way"***

For an initial enquiry or to book your place, contact:

**steve@rareminds.org / 07792 782374**

**Steve Smith** works within 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 the Mindfulness Lead for Rareminds www.rareminds.org and a Trainer/Supervisor for Breathworks www.breathworks-mindfulness.org.uk He is passionate about the benefits of Mindfulness as a practical tool for everyday living.

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**

IMMUNO DEFICIENCY UK | Supporting families affected by primary and secondary immunodeficiency

rareminds
Mental Health for the Rare Disease Community

We're excited to announce that a few spots remain in our upcoming 8-week mindfulness course. This program, fully funded by Immunodeficiency UK, is specifically designed for individuals living with primary and secondary immunodeficiency who may be struggling with pain, fatigue, or anxiety.

**Course Details**

**Dates**: Weekly on Thursdays, October 10th to November 28th, 2024
Time: 7:00 PM to 9:00 PM
**Platform**: Zoom
**Instructor**: Steve Smith, experienced RareMinds mindfulness practitioner
**Group Size**: Maximum of 15 participants (Limited spots still available!)

**What You'll Learn**

- Mindfulness strategies to cope with pain, fatigue, and anxiety
- Ways to cultivate a calmer, kinder way of living with your condition
- Practical tools for everyday mindful living

**Previous participants have shared their positive experiences:**

*"Fantastic course. Helped with many coping strategies and managing anxiety, fear of illness, fatigue and over doing things. Meditation is a wonderful thing I have discovered and the whole learning process was made so great by a fantastic teacher."*

*"I found the course really valuable; the teacher was very patient and knowledgeable, and it helped immensely to be in the room with other people with a similar condition to mine."*

**Don't miss out on this opportunity! To secure one of the remaining spots:**

1. Commit to approximately 20 minutes of daily practice
2. Purchase the Course Handbook (£10) from Amazon or other online retailers
3. Contact steve@rareminds.org or call 07792 782374 TODAY to reserve your spot.

Please note that spaces are filling up quickly, and we ask for your commitment to completing this Immunodeficiency UK funded course, which costs the charity approximately £225 per person.

# The Generation Study – Groundbreaking Newborn Screening Research

Exciting developments are underway in newborn screening! The Generation Study, a collaborative effort between Genomics England and NHS England, is exploring the potential of whole genome sequencing to revolutionise how we screen newborns for genetic conditions.

**What's New?**

- Expanded Screening: The study aims to screen for over 200 childhood-onsetgenetic conditions, including numerous primary immunodeficiencies (PIDs) linked to more than 100 genes. See the list of PIDs being screened for here.

- Nationwide Reach: Starting with 5 NHS trusts and expanding to 25-40 acrossEngland, the study will run until March 2025. The sites have been chosen based on birth volume, the diversity of people who use the hospital and the maternity department performance. The study is expected to run until March 2025.

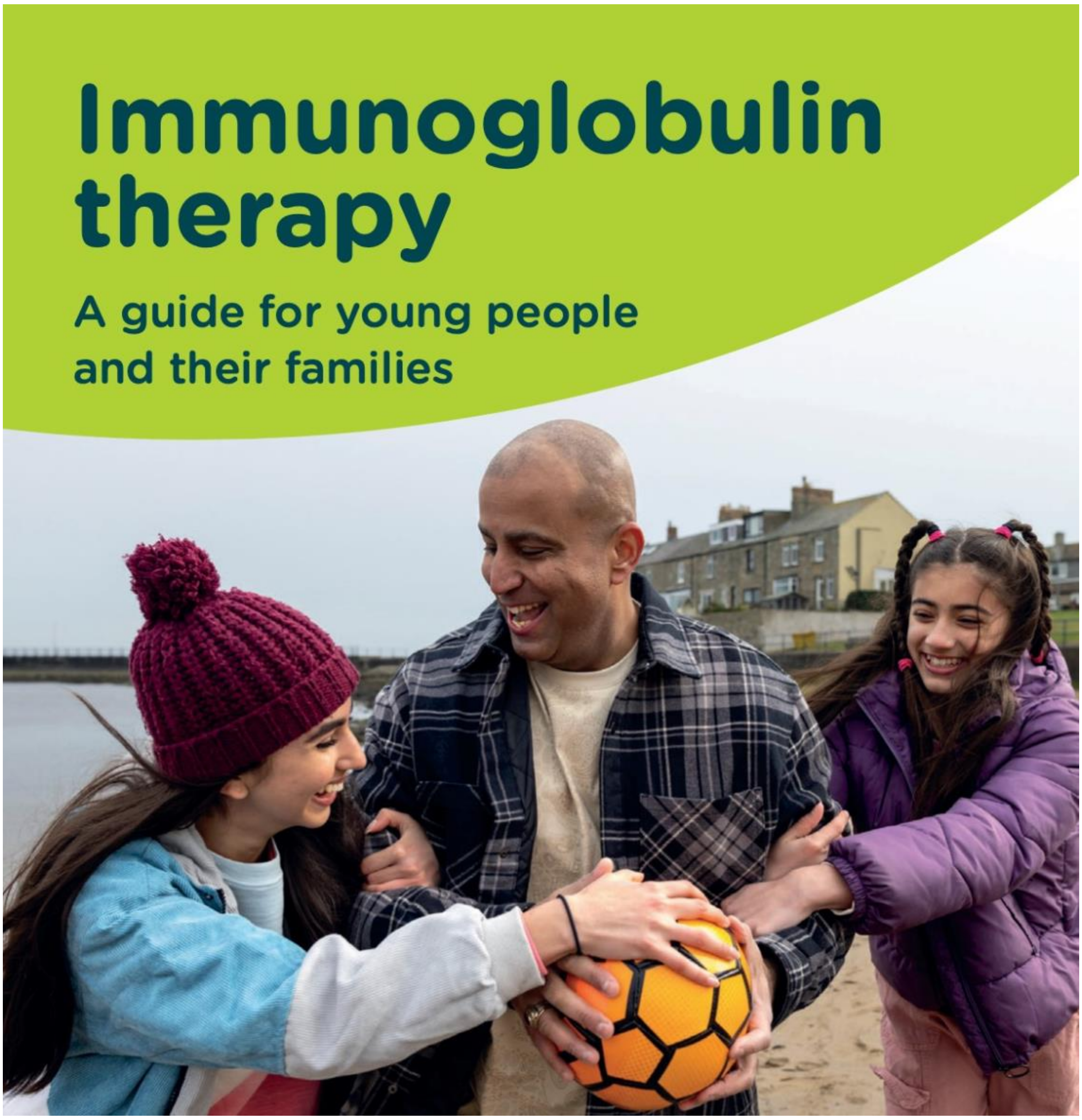
- Immunodeficiency UK's Role: We've partnered with Genomics England todevelop information sheets once a suspected condition has been detected but before confirmatory testing has been done, and we're the designated support organisation for these families.

**Get Involved and Learn More**

Visit Immunodeficiency UK's Generation Study page.

This groundbreaking research could pave the way for earlier diagnoses and interventions, potentially transforming outcomes for babies born with primary immunodeficiency and other genetic conditions. Stay tuned for updates as this exciting study progresses!

## New Guide for Young People & Parents on Immunoglobulin Therapy



Immunoglobulin therapy

A guide for young people
and their families

We are excited to introduce our latest resource: Immunoglobulin Therapy – A Guide for Young People and Their Families.

This comprehensive guide is designed to support young people and their families as they navigate the complexities of immunoglobulin therapy.

**What You'll Find in the Guide:**

- Understanding immunoglobulin treatment: A clear explanation of whatimmunoglobulin is and how it supports the immune system. - Treatment options: Detailed information on intravenous (IVIG) and subcutaneous (SCIG) immunoglobulin therapies, including what to expect during treatment.

- Making the right choice: Guidance on choosing the best treatment optionbased on your lifestyle and medical needs.
- Ongoing support: Tips on managing treatment at home, including how to safelyadminister therapy and what to expect during follow-up care.

This guide was developed with top hospitals and community feedback, it's a goto resource for young people navigating immunoglobulin therapy.

Download it here.

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## Share Your Bone Marrow Transplant Journey

We are reaching out to those who have undergone a bone marrow transplant as part of their treatment for primary immunodeficiency. Your experiences are invaluable, and we want to share them to inspire, educate, and support others in our community.

**Why Share Your Story?**

Provide hope and encouragement to those facing a transplant
Help others understand the transplant process and recovery

- Raise awareness about the challenges and triumphs of living with immunodeficiency

**What We're Looking For**

We welcome stories at any stage of the transplant journey, including:

- Pre-transplant experiences and decision-making
- The transplant process itself
- Recovery and post-transplant life
- Long-term effects and quality of life improvements
- Challenges faced and overcome
- Advice for others considering or preparing for a transplant

If you're willing to share your story, please email us at hello@immunodeficiencyuk.org

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Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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