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Welcome to the February Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the February newsletter.

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 [like us on Facebook](#) to get updates throughout the month.

Your voice matters! Help shape the future of mental health support for our community

We'd love for you to be part of our important mental health survey. We want to get a real understanding of how everyone's doing – your feelings, your worries, what support helps you cope, and even how things like COVID-19 have impacted your wellbeing.

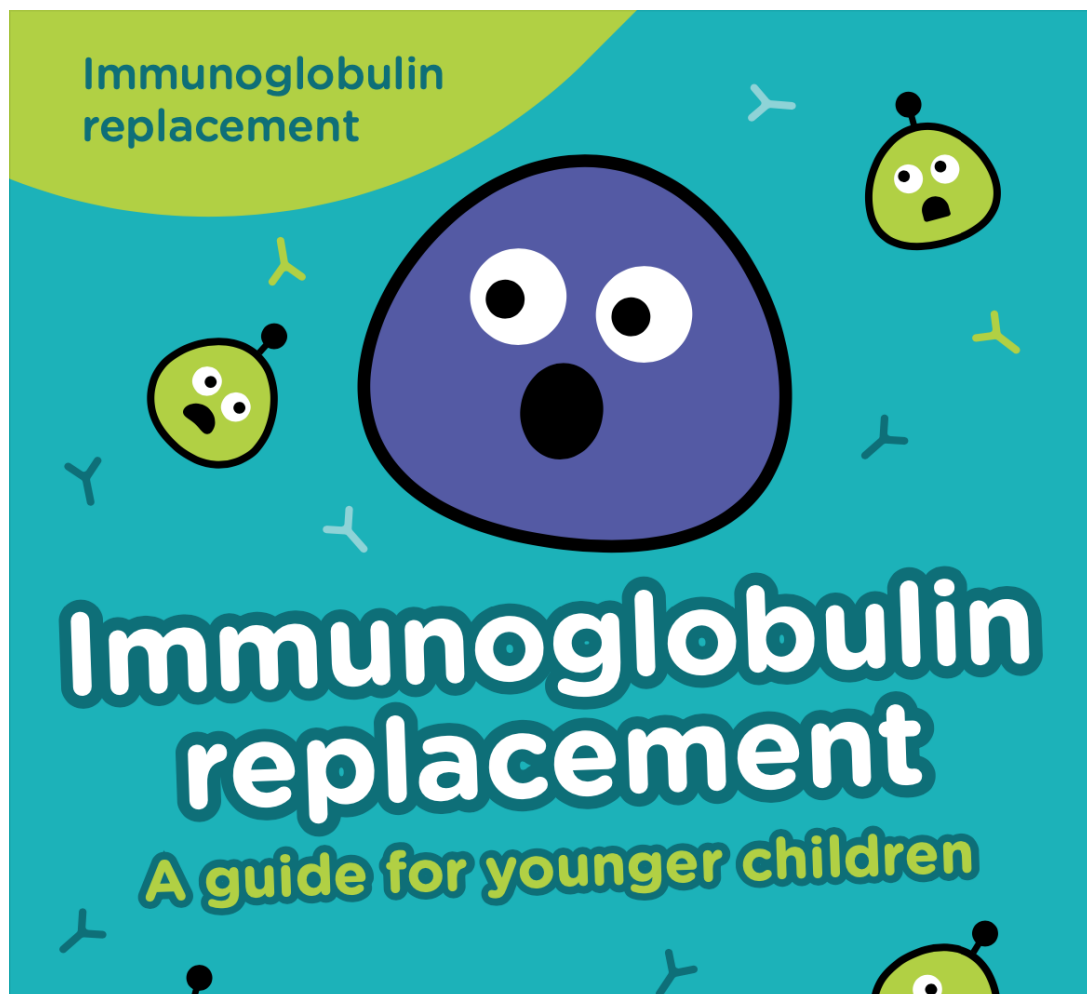
Why are we doing this? Because we want to make sure we're getting the right support out there for people living with immunodeficiency. Your answers will help us work out exactly where to focus our efforts and how to make a real difference.

Don't worry, it's completely private. We won't ask for your name or anything that could identify you.

The survey should only take about 10-15 minutes, and we need anyone over 16 to take part. Be honest – we want your real experiences, good and bad. [Visit this link to access the survey.](#)

Thank you so much for taking the time to do this. Together, we can build a stronger understanding of mental health and create the best possible support for our whole community!

NEW Immunoglobulin guide for children



We are thrilled to launch our latest booklet, 'Immunoglobulin Replacement – a Guide for Younger Children', created in collaboration with Great Ormond Street Hospital and the Great North Children's Hospital.

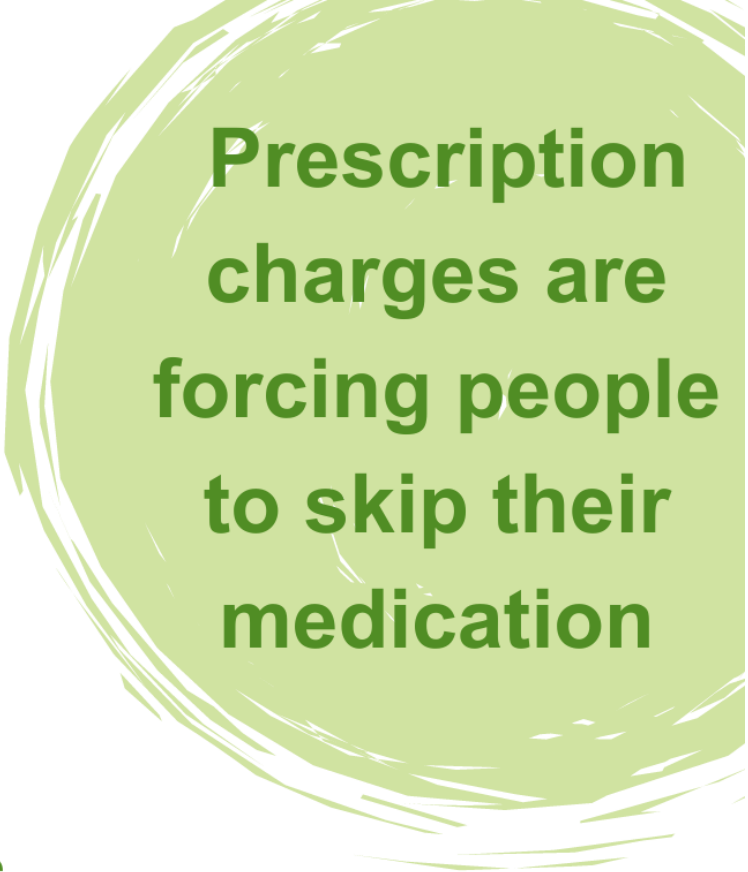
This comprehensive guide is designed to provide information and support for young children navigating immunoglobulin (IG) treatment in a fun and friendly way.

Visit [our website](#) to download this new guide and contact us at hello@immunodeficiencyuk.org if you would like a printed copy.

Thank you to Great Ormond Street Hospital and the Great North Children's Hospital for their invaluable collaboration and to the young people and parents who helped to make this leaflet and bring this resource to life.

Together, let's continue to champion support and awareness for children with immunodeficiency. We're here for you every step of the way.

 **Attention: Take Action to #FreezeTheCharge!**



**Prescription
charges are
forcing people
to skip their
medication**

#FreezeTheCharge

The Prescription Charges Coalition, of which Immunodeficiency UK is a member, is urgently calling on the UK government to freeze the prescription charge in England for both 2024 and 2025.

Many of those living with immunodeficiency and other long-term conditions such as Parkinson's, Multiple Sclerosis, arthritis, asthma, cystic fibrosis, motor neurone disease, and HIV, rely on multiple medications daily. Unfortunately, working-age individuals with these conditions cannot apply for exemption from prescription charges.

This poses a significant concern as the increased cost may force individuals to make unbearable choices between essential medication, basic necessities like food and heating, and overall well-being. In a [recent article](#) pharmacists have warned they are increasingly seeing patients in England declining to take vital medicines due to the cost of prescription charges.

You have the power to make a difference! Please add your name to the open letter addressed to the government and join the campaign to #FreezeTheCharge.

Together, let's ensure access to vital medication remains affordable for all who need it. Please sign the petition now: [Petition Link](#)

Your support is invaluable in advocating for the rights and well-being of individuals living with immunodeficiency and other chronic conditions. Let's stand together to make our voices heard!

Arabella's Story: Coping with APDS



Arabella, a once healthy baby, struggled with a persistent illness that baffled doctors for years. Finally, a referral to Great Ormond Street Hospital (GOSH) revealed the diagnosis: activated P13K delta syndrome (APDS), a rare condition affecting multiple body systems.

Through immunoglobulin therapy and medication, GOSH has significantly improved Arabella's health. However, the threat of lymphoma looms, and the family is urgently seeking a bone marrow donor for a potential cure.

Despite the immense challenges APDS brings, Arabella's bravery and beautiful smile serve as a constant inspiration. Her family aims to raise awareness of APDS and support others facing similar challenges.

Dealing with transition



Managing Transition: A Survival Guide for Parents and Carers

Date: Tuesday 19th March 6.00pm – 7.30pm
Location: Zoom

This small group workshop on managing the transition from children services to adult care is facilitated by Kym Winter, Psychotherapist and Rareminds CEO.

The move from children's to adult services can be challenging for both parents and young people in different ways. Supporting your young person to become more independent with the care around their condition can feel a nerve-wracking task, especially when combined with the 'ups and downs' of the teenage years, or if there are developmental or cognitive issues involved too.

"An excellent session with insightful, useful, practicable topics with useable interventions and actions." (Managing Transition Workshop participant 2022)

This interactive workshop provides an informal relaxed space to share thoughts, feelings and fears about this process with other parents. It will include information and tips about adolescent emotional development, teen communication skills, and preparing for and navigating the change to adult care.

If you would like to know more in advance, please do contact the Workshop Facilitator on kym@rareminds.org



Kym is the Clinical Director and Founder of *Rareminds*, a UK based charity providing specialist psychotherapy, counselling and emotional wellbeing resources to rare disease communities. A psychotherapist for nearly 30 years across the NHS, higher education and UK third sector, she has worked with individuals, couples, leaders and healthcare professionals impacted by rare diseases since 2013. She also has lived experience of a rare genetic condition in her immediate family.

To reserve your place please email Immunodeficiency UK at hello@immunodeficiencyuk.org


We look forward to seeing you there!

rareminds
Mental Health for the Rare Disease Community

Is your child facing the daunting transition from children's services to adult care?

Join us for an interactive workshop, "Managing Transition: A Survival Guide for Parents and Carers," facilitated by Kym Winter, Psychotherapist and Rareminds CEO.

 Date: Tuesday, March 19th

 Time: 6:00 pm – 7:30 pm

Navigating the shift from paediatric to adult services can feel overwhelming, especially amidst the complexities of adolescence or when dealing with developmental or cognitive challenges. But fear not! This workshop is designed to equip you with the tools and support you need through this critical transition as parents and carers.

Here's what you can expect:

🤝 Supportive environment: Connect with fellow parents and carers who understand the unique journey you're on, fostering a sense of community and solidarity.

🎓 Expert guidance: Benefit from Kym Winter's wealth of experience as she shares practical insights and strategies to help you navigate this transition with confidence.

💬 Interactive discussion: Engage in open, honest conversations about your thoughts, feelings, and fears surrounding the transition process, gaining valuable perspectives and advice.

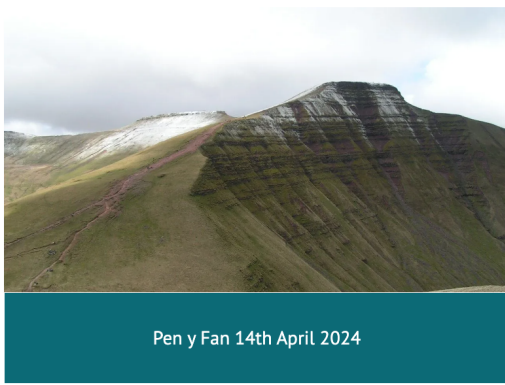
🔍 Informative session: Learn about adolescent emotional development, effective communication skills for teens, and how to prepare for and navigate the shift to adult care.

Don't just take our word for it! Here's what a past participant had to say: "An excellent session with insightful, useful, practicable topics with usable interventions and actions."

To reserve your place and secure your spot in this workshop, simply email Immunodeficiency UK at hello@immunodeficiencyuk.org. Spaces are limited, so don't delay!

For any inquiries or to learn more in advance, feel free to reach out to the Workshop Facilitator, Kym, at kym@rareminds.org. We hope you will take part in an empowering evening of learning, sharing, and support.

**Take on a new challenge for Immunodeficiency
UK**



Pen y Fan 14th April 2024



The Edale Skyline Challenge 27th April 2024



Snowdon adventure 9th June 2024



Snowdon 22nd June 2024

Are you ready to take on a thrilling adventure while making a difference? Look no further than Immunodeficiency UK Challenges, brought to you by Elite Adventures! Gear up for an exhilarating journey through breathtaking landscapes, all while raising awareness and funds for Immunodeficiency UK.

Whether you're a seasoned hiker or a novice, there's a challenge tailored just for you.

Here's what you can expect:

🌟 **Unforgettable Routes:** Traverse through stunning terrains, from scenic trails to urban landscapes, offering a unique experience with every step.

🌟 **Support a Worthy Cause:** Your participation directly supports Immunodeficiency UK's vital work in providing support, information, and advocacy for individuals and families affected by primary immunodeficiency disorders.

🌟 **Join a Community:** Connect with like-minded individuals passionate about fitness, adventure, and making a positive impact in the world.

Receive recognition for your fundraising efforts, with every pound raised contributing to a brighter future for those living with immunodeficiency. Ready to embark on this incredible journey? Sign up now and be part of something truly extraordinary! View the full range of challenges [here](#).

Best Wishes,
Susan and Fay
The Immunodeficiency UK Team

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