



## May Newsletter

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# Welcome to the May Immunodeficiency UK newsletter!



Hello Immunodeficiency UK member,

Welcome to the May 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.*

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## Trustee vacancies at Immunodeficiency UK



We are looking for at least two independent senior volunteers our Board, to bring fresh ideas and perspectives to what we do and make us as effective as possible as a team.

We are looking for experienced members of the public to join our Board of Trustees on a voluntary basis to help steer our growth over the coming years and who will ensure adequate governance oversight of our much-needed services.

We are particularly keen to recruit people who have one or more of the following skills:

- Experience of living or caring for a person with an immunodeficiency
- Charity sector experience
- Organisational governance
- Risk management

Board meetings are currently held online every two months and take place on a Monday evening starting at 5pm for one to two hours. To find out more visit <https://www.immunodeficiencyuk.org/immunodeficiency-uk-trustee-vacancies/>

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# Thank you to Grifols

We are grateful to Grifols who have made a donation to sponsor our e-newsletters for the next year.

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## Sophie and Micky's Mighty Hike



In [last month's newsletter](#) we featured the story of Sophie and Jasper. In August 2023 Jasper was found to be the only known child in Wales with rare primary immunodeficiency APDS, caused by the PIK3CD mutation.

Inspired by Jasper's courage and the unwavering support of the immunology team, Sophie and her friend Micky have embarked on a remarkable fundraising journey. From conquering Pen-Y-Fan to tackling the 7 Lake District Peaks, their ultimate challenge will be a mighty 135-mile hike around Anglesey in May, all in support of Immunodeficiency UK.

Through their efforts, Sophie and Micky aim to raise funds and awareness for primary immunodeficiencies, empowering families to trust their instincts and advocate for their loved ones when faced with unexplained symptoms.

Join us in supporting Sophie and Micky's remarkable journey by donating to their Mighty Hike and contributing to the vital work of Immunodeficiency UK. Your generosity will not only honour Jasper's resilience but also pave the way for a brighter future for countless families facing the challenges of primary immunodeficiency disorders.

To donate, please visit: <https://www.justgiving.com/page/sophie-micky-mighty-hike>

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## The role of the lay assessor in QPIDS accreditation



My name is Jeffrey Goodwin, and I am a Lay Assessor and Member of the Steering Group for the Royal College of Physician's Quality in Primary Immunodeficiency Services (QPIDS) accreditation programme.

Quality in Primary Immunodeficiency Services (QPIDS) is the accreditation programme for primary immunodeficiency services in the UK. Services undergo a programme of quality improvement before receiving a rigorous assessment against the QPIDS standards. Services which are shown to meet the standards are granted accreditation. Fundamental to the process is the role of the Lay Assessor.

Accreditation involves evaluating a service against a set of standards to promote a culture of continuous improvement, thereby providing assurance to patients, referrers, and commissioners about the quality of the service provided.

The lay assessor is a member of the accreditation assessment team and plays a full part in evaluating a service. The team will have an immunology consultant, an immunology nurse and the lay assessor. Each member has a particular role in evaluating a service. We all receive the same evidence and work to evaluate against the same set of standards as set by QPIDS. Each of us views the standards from our own perspective; for the lay assessor this means reviewing the patient experience as reported by the service and interviewing a small group of patients to understand their experiences of the service. Whilst we are looking to identify any areas that need attention, we are also looking to highlight areas of best practice. Our aim is to support the service to improve for the benefit of the patients. If you would like more details about QPIDS, go to [www.qpids.org.uk](http://www.qpids.org.uk) where you will find detailed information about this part of the Accreditation Unit.

I have been a hospital patient for some 40 years and, having started working for myself, I realised that I could manage my time to contribute to improving the patient experience. I believe that it is very important for the patient voice to be heard. In my role, I can look to understand the way a service collects and reviews patient feedback and identify where the role of the patient can be more effectively used to make quality improvements. There is an opportunity to evaluate the patient pathway by considering a range of evidence, including: the invitation letter,; the experience at the hospital; the feedback the patient receives; and, the overall support for their condition.

We are fully supported by the QPIDS accreditation team who provide both administration and operational support. Lay assessors have meetings to share experiences and make recommendations for improvements to the accreditation processes. The whole process is run professionally and it is a pleasure to be part of a team who are looking to improve the patient experience.

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## Navigating Life with an Immunodeficiency: Immunodeficiency UK's Lifestyle Resources Hub



Living with an immunodeficiency can present various challenges, but our lifestyle resources hub is here to support you every step of the way.

This comprehensive online resource centre offers a variety of helpful guides and information to help you maintain your well-being, maximise your healthcare experiences, and navigate various aspects of daily life. [Below you'll see details for just a few of the available guides:](#)

**Keeping Well and Healthy:** Discover practical tips and strategies to stay healthy, manage your condition effectively, and improve your overall quality of life.

**Making the Most of Your Appointments:** Learn how to prepare for and make the most of your medical appointments, ensuring effective communication with your healthcare team and addressing your concerns.

**Going on Holiday:** Plan your holidays with confidence by accessing guidance on travelling with an immunodeficiency, including information on insurance, medication management, and staying safe while enjoying your time away.

**Insurance Matters:** Find advice on obtaining suitable policies, and learn about your rights and options.

**Your Employment Rights:** Gain insights into your legal rights as an employee with an immunodeficiency, ensuring a fair and supportive work environment.

From practical tips to legal guidance, our Lifestyle Resources Hub is your go-to source for information. Visit the hub at [www.immunodeficiencyuk.org/resources/lifestyle-resources/](http://www.immunodeficiencyuk.org/resources/lifestyle-resources/) to access these valuable resources and take control of your well-being.

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## New Plan to Expand Children's Access to Gene Therapies



Great Ormond Street Hospital (GOSH) has announced an innovative plan to help more children gain access to life-changing gene therapies for rare diseases such as primary immunodeficiency. The challenge is that developing treatments for rare diseases is often not commercially viable for companies due to small patient numbers.

GOSH aims to address this by exploring having the hospital hold the licenses and market authorisation for proven gene therapy drugs. This would be the first time an NHS Trust has held such licenses, allowing direct patient access.

The pilot program will focus on a lentiviral gene therapy for ADA-SCID, a rare immune disorder. If successful, the model could expand to provide other transformative gene therapies to children with inherited diseases at GOSH and beyond. Partners include LifeArc, a charity overcoming hurdles in getting rare disease treatments to patients, and GOSH Charity, funding pioneering research.

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## Radar Keys: Unlocking Accessibility for the Immunodeficiency Community



For those living with immunodeficiency accessing accessible toilets can make a huge difference in maintaining health and dignity. Immunodeficiency UK's Radar Keys provide a vital solution at just £4.

These durable keys allow entry to the 9,000+ disabled toilet facilities across the UK installed with a National Key Scheme (NKS) lock.

Each £4 Radar Key purchase supports Immunodeficiency UK's mission to improve lives through education and advocacy. [Order your Radar Key today.](#)

You can find RADAR key toilet locations near you by using the [Great British Public Toilet Map](#). Simply go to the filter on the left-hand side of the homepage and filter by 'Radar key'.

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## Our recent advocacy activities



Here are some of advocacy activities on behalf of people affected by immunodeficiency:

We responded to the Welsh Health Specialised Services consultation on specialised immunology services; the Department of Health and Social Care consultation on further amendments to the Statutory Scheme for Branded Medicines Pricing and Access supporting an exemption for blood and plasma products and the NHS England clinical commissioning proposition on the use of Abatacept for autoimmune complications caused by CTLA-4 or LRBA genetic mutations.

Susan, our CEO, and Alison, one of our patient representatives, attended the House of Commons to represent Immunodeficiency UK at the 'I am number 17' campaign's parliamentary event, which was organised and funded by Takeda in collaboration with other charity partners including us. The aim of the reception was to launch the 'policy solutions' that focus on some of the central challenges faced by the rare disease community. If you would like to learn more about the campaign, [visit their website](#).

We were delighted to hear that our advocacy activity, in collaboration with Genetic Alliance UK and Great Ormond Street Hospital, resulted in the primary immunodeficiency Schimke immuno-osseous dysplasia being licensed for pre-implantation genetic testing (PGT). PGT can be used by people who have a serious inherited disease in their family to avoid passing it onto their children.

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## Progress update on our Patient Experience Survey

We are pleased to let you know that the Patient Experience Survey results have now been analysed. We would like to thank again everyone who took the time to participate and share their feedback in our Patient Experience Survey. The insights gathered will be invaluable in shaping our understanding of patient experiences and informing future initiatives.

Following a full analysis of the results, we are now in the process of developing a comprehensive report and an executive summary detailing the key findings and trends from your responses and recommendations to policymakers on actions they should take to improve care and quality of life for patients with immunodeficiency.

We anticipate the report and executive summary will be finalised and ready for publication later this summer. Keep an eye out for further updates on the exact release date and how you can access these valuable resources.

By way of reminder, the survey was conducted independently by the healthcare communication consultancy, Interaction Marketing & PR. The report is subsequently being authored by the independent healthcare policy and communications consultancy, Incisive Health. Both initiatives were developed in collaboration between Immunodeficiency UK and Takeda UK Ltd., with funding provided by Takeda UK Ltd.

If you have any questions regarding the survey or report, please reach out to [admin@iduksurvey2023.co.uk](mailto:admin@iduksurvey2023.co.uk).

Thank you again for your continued patience and support!

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Best Wishes,  
Susan and Fay  
The Immunodeficiency UK Team

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