

UK ADULT ITP REGISTRY NEWSLETTER



Issue 013

DEC 2025

WELCOME

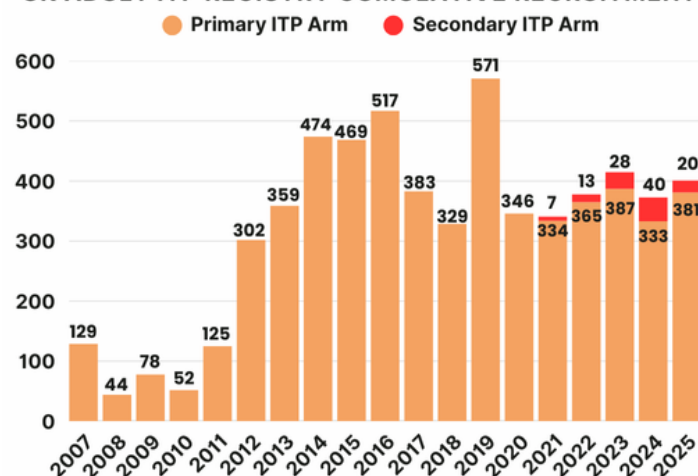
Hello and welcome to the latest edition of the UK Adult ITP Registry Study Newsletter. Thank you to all sites and research staff for their ongoing support and hard work.

The biggest update in this issue is that we are delighted to announce an extension to the study timelines. The **recruitment end date has been extended to 31 December 2030**, and the **overall study end date is now 31 December 2031**. All sites should have received an amendment notification email (**non-substantial amendment 65**) containing further information on how to process this amendment locally.

Recruitment continues to be strong. To date, we have recruited **5,976 participants** in the primary ITP arm and **110 participants** in the secondary ITP arm. In addition, **133 participants** have been enrolled in the pregnancy registry.

A full breakdown of recruitment numbers by site and region is available via the [Tableau dashboard](#).

UK ADULT ITP REGISTRY CUMULATIVE RECRUITMENT



<https://www.qmul.ac.uk/itpregistry/>

REDCap database

The study database is accessible via redcap.qmul.ac.uk. If you experience any difficulties accessing the database or have questions about data entry, please do not hesitate to contact us. User guides are also available for download from our [website](#).

As a reminder, once a participant has consented to the study, please send a copy of the consent form(s) to the registry team along with an updated site participant log. Baseline/diagnostic data should be entered into REDCap within six weeks of consent, and follow-up data should be updated at least once annually.

We encourage all sites to regularly review the '**Resolve Issues**' link in REDCap to identify any fields or forms requiring completion or correction. When addressing queries, please use the dialogue box to confirm that the query has been resolved and select the appropriate response from the drop-down menu. This will notify the registry team to review and close the query.

Please note that if queries are not responded to in this way, we will not be notified of the updates, and the query will remain unresolved.

If you would like to receive exported data for specific forms or participants (in Microsoft Excel format) to support data entry, please let us know, and we will be happy to provide it.

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Meetings and presentations

This year, we were pleased to share important updates from the UK ITP Registry at the annual BSH, EHA and ASH conferences:

- **Susceptibility To Bleeding In ITP Is Not Increased In Elderly Patients: Evidence From The UK ITP Registry** – EHA poster presentation by Dr Chen.
- **Fostamatinib for the Treatment of Refractory ITP: Data from the UK Adult ITP Registry**. Tsiamita et al – BSH oral presentation by Dr Olga Tsiamita
- **Audit of change in non-corticosteroid treatment in ITP: an analysis of the UK ITP Registry**. BSH oral presentation by Dr Chen.
- **Closing analysis of the patient and disease characteristics of the UK Primary Paediatric ITP Registry**. ASH poster presentation by Dr Mia Giles.

We also took part in the **annual ITP Update Day** and the **ITP Support Association Annual Convention**, where Dr Chen presented further updates from the registry.

Feedback from colleagues across the UK and internationally was overwhelmingly positive and encouraging. We look forward to building on these projects and aim to submit manuscripts for publication over the next 12 months.

Celebrating 30 years of the ITP Support Association

This year marks a special milestone for the **ITP Support Association as it celebrates its 30th anniversary**. To mark the occasion, we were honoured to attend a reception at the Palace of Westminster, hosted by Richard Fuller MP, celebrating the association's vital work in raising awareness of ITP and supporting those affected by this rare autoimmune condition.

The UK ITP Registry has been fortunate to receive steadfast support from the ITP Support Association over many years. Their dedication has been instrumental in helping us reach our goals and improve outcomes for patients across the UK.

We extend our heartfelt congratulations to the ITP Support Association on this remarkable anniversary and look forward to continuing our close collaboration in the years ahead.



From left to right: Dr Frederick Chen, Dr Drew Provan, Prof Adrian Newland, Haroon Miah, Louise Taylor, and Atiqah Miah at the reception at Westminster celebrating the 30th anniversary of the ITP Support Association.



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New Publication from the UK Adult ITP Registry

The UK Adult ITP Registry contributed the largest cohort to a major European study of over 5,000 adults with ITP, drawing on national registries from the **UK, France, Italy, Norway, Germany, and Switzerland/Serbia**, and recently published in **Haematologica** as **"Use of second-line and beyond maintenance therapies in adult patients with primary immune thrombocytopenia in Europe: a parallel study of six prospective multicenter national registries."**

The study demonstrates increasing use of thrombopoietin receptor agonists, alongside reduced use of rituximab and splenectomy, reflecting changing clinical practice across Europe. This collaboration highlights the value of UK registry data in generating high-impact evidence to inform patient-centred ITP care.



Impact of antiphospholipid antibodies in patients with ITP

The ITP Registry has launched a new research project to investigate the role of antiphospholipid antibodies (APL Abs) in predicting thrombotic risk in patients with ITP. APL Abs are present in up to 20–40% of ITP patients, yet their clinical significance, particularly in the context of increasing use of thrombopoietin receptor agonists (TPO-RAs), remains unclear.

Using longitudinal registry data, this study will examine the relationship between APL Abs, cardiovascular risk factors, ITP treatments, and thromboembolic events. Preliminary evaluation has identified 800–1,000 patients with APL Ab testing, and the project is supported by a £5,000 ITP Forum grant.

Sites will be contacted to help update key laboratory, treatment, and outcome data for eligible patients. This high-impact study aims to clarify the value of APL Ab testing in ITP and support more individualised, risk-based patient care. Participating sites will be offered authorship or PubMed-citable collaborator status, in line with journal requirements.

If blood samples are being sent to the registry office, please complete the 'specimen transfer form', and enclose it with the samples. Full details can be found on our website via:

<https://www.qmul.ac.uk/itpregistry/study-documents/study-blood-samples/>

The registry office will be closed from 22nd December 2025 to 4th January 2026; please do not send any samples during this time.