

THE UK ADULT ITP REGISTRY NEWSLETTER NOV 2023



WELCOME

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



We'd like to start off the newsletter by informing all sites of a change in leadership for the study. Dr Frederick Chen (inset) has assumed the role of Chief Investigator (CI), succeeding Dr Vickie McDonald. Dr Chen brings a wealth of experience and expertise to this position and we are confident in his ability to lead the study to successful outcomes.

We want to extend our heartfelt appreciation to Dr Vickie McDonald for her dedicated leadership and contributions during her tenure as CI. Her efforts have played a pivotal role in advancing the study and we are grateful for her commitment.



RECRUITMENT

As of 30th October 2023, **5285 patients** have been consented to the Main Adult ITP Registry and **91 patients** have been consented to the pregnancy arm (Charts 1 and 2).

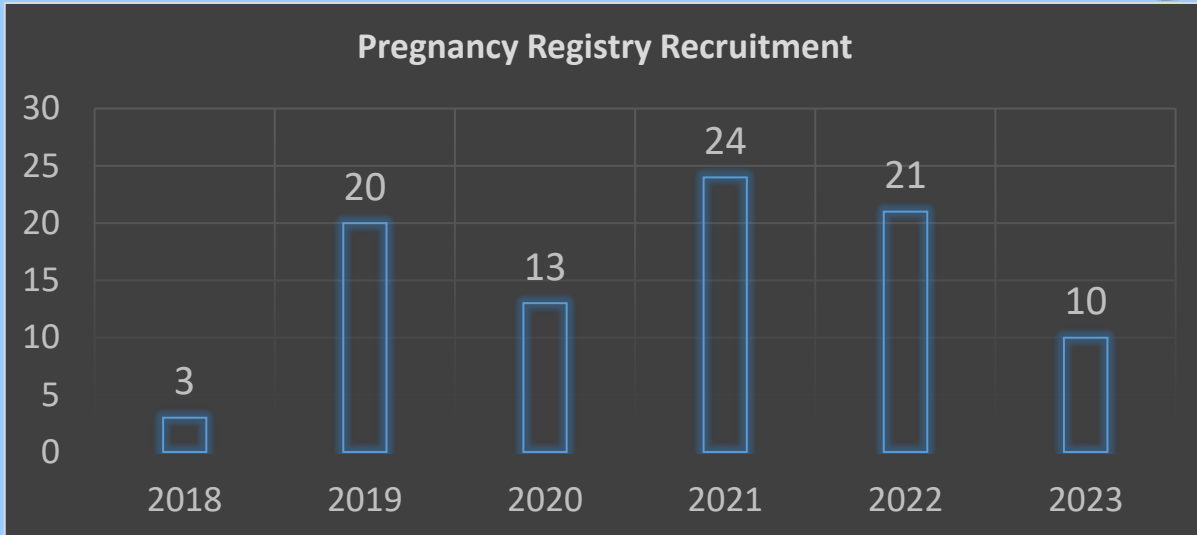
The third arm for **secondary ITP** is live on REDCap. Sites may recruit eligible patient for this arm and enter data accordingly. The study recruitment end date is **31st December 2024**.

Chart 1. Patient recruitment in the main UK Adult ITP Registry

UK Adult ITP Registry Recruitment



Chart 2. Patient recruitment in the Pregnancy Registry



REDCap DATABASE

Please continue to check the ‘Resolve Issues’ link on REDCap to review which fields/forms have been queried or need completing. When completing queries on REDCap, please ensure that you respond to the query using the dialogue box to confirm that the query has been addressed using the relevant response from the drop down boxes:

Registry Identification Code (RIC) : [XTS10316](#)
 Event: **UK ITP Registry (Arm 1: UK ITP Registry)**
 Field: **dose_unit_5** ("Unit of Dose")
 Status: 🚫 **Open / Unresolved** (unresponded)

Date/Time	User	Comments and Details
27/04/2020 1:42pm	hmiah	Action: Opened query Comment: "Please complete"
17/07/2023 3:05pm	testuser	Reply with response: <input type="text" value="Other"/> Upload file (optional): Upload document Comment: <input type="text" value="Data entered now."/>

This will then send a notification to the registry team to review the response and close out the query. If the query isn't responded to like this, we will not be notified of the updated data being added to the field and the query will remain unresolved. If you have any questions regarding this, please contact the registry team.

Blood Samples:

We have created a 'specimen transfer form', which is to be used when sites send samples to the registry study laboratory. Full details can be found on our website via:

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

PUBLICATIONS AND PRESENTATIONS



British Society for Haematology Annual Scientific Meeting – April 2023:

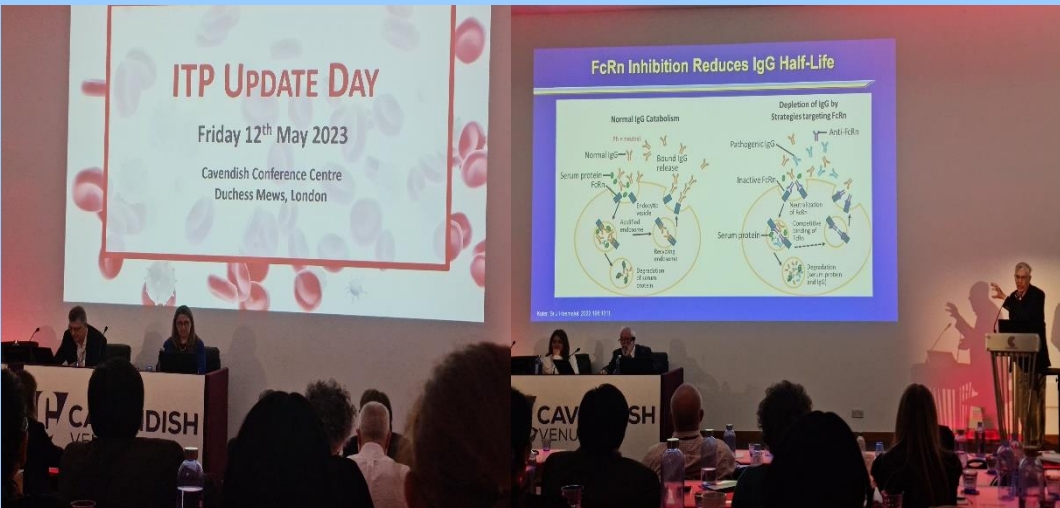
Our abstract titled, 'Thrombopoietin receptor agonists (TPO-RAs) in older patients with primary immune thrombocytopenia (ITP): effective and safe? Real World Data from the UK Adult ITP Registry', was presented as a poster.

ITP Update Day – May 2023:

The registry team attended the annual ITP Update Day in London, held by Hartley Taylor. The meeting provided an update on new treatments, with a look at new drugs entering the treatment of ITP, along with sessions focusing on dealing with uncertainty, difficult cases and horizon scanning. Our very own Dr McDonald presented an update on the ITP Registry.

ITP Support Association Annual Convention – May 2023:

The annual convention organised by the ITP Support Association brings together patients and experts from around the world to discuss the latest developments and updates relating to primary ITP.



A full list of all presentations and publications can be found on our website: <https://www.qmul.ac.uk/itpregistry/latest-news-events-and-links/publications-and-presentations/>



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COMMUNICATIONS

Head over to <https://twitter.com/UKITPR> and support our Twitter/X page. We'll be using this platform to shine a light on ITP with the latest news/publications and promote any upcoming events. #ITPAware #ITPRegistry!

You can also visit our Website: <https://www.qmul.ac.uk/itpregistry/>