THE UK ADULT ITP REGISTRY NEWSLETTER

Dec 2020

WELCOME

Hello and welcome to the latest edition of the UK Adult ITP Registry Newsletter. It's been quite an unpredictable period since the pandemic started back in March, affecting research and routine healthcare as a whole but there is still plenty to update about.

RECRUITMENT

As of 30th November 2020, 4230 patients have been consented to the Registry. Inevitably, the numbers have been affected by the pandemic and lockdown measures, however, we have worked to mitigate this by implementing remote consenting; enabling sites to consent patients without requiring face-to-face contact.

The non-substantial amendments updating the protocol, participant information sheets and consent forms have been approved by HRA and have been sent to all sites to approve locally before implementing.

If you have any questions or require any further information regarding this, please get in touch.

REDCap DATABASE

To help sites deal with any queries or missing data in the REDCap database, we have activated a feature called the 'Query Resolution Workflow'.

This is a feature within REDCap where we will be able to review the data that has been entered by sites and then flag up or highlight any data gaps or errors that need to be addressed. Site staff will then be able to review any queries by clicking on the 'Resolve Issues' link on the left hand side of the main screen after logging into REDCap, under 'Applications'.

For any questions where the data is missing or unavailable, please enter, '9999' for numeric fields and '01/01/1000' for date fields. Examples can be found in our REDCap user guides.

ITP PREGNANCY REGISTRY UPDATES

Since its commencement in August 2018, 31 women have been recruited to the pregnancy arm of the UK Adult ITP Registry (See Figure 1.0, 20Nov2020).

Pregnancy ITP is a rare overall occurrence and using the pre-existing infrastructure of the UK ITP Registry has allowed a linked dataset to further our knowledge in this area. Analysis of data gathered over the last two years (Raheja et al., 2020) has demonstrated its usefulness in providing invaluable insight on the management and outcomes of patients with ITP in pregnancy.

As you might be aware, we conducted a review of the pregnancy registry data earlier this year and flagged missing data queries to all relevant sites participating in this arm of the registry in October 2020. Please review and enter data onto REDCap if you haven't done so already.
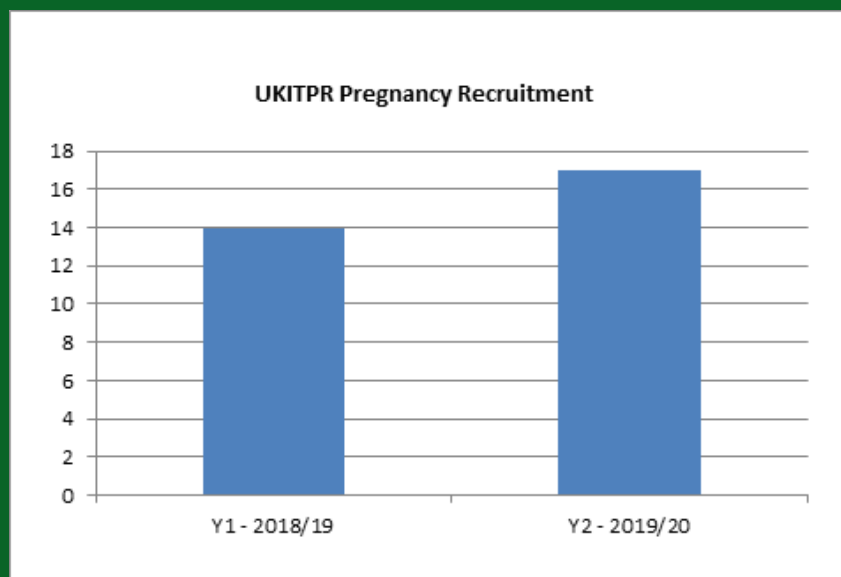
Thank you for all your hard work!

Figure 1.0: *UKITPR Pregnancy Recruitment by Year (20Nov2020).*

LATEST PUBLICATIONS & PRESENTATIONS

Fostamatinib: a review of its clinical efficacy and safety in the management of chronic adult immune thrombocytopenia. Adrian Newland and Vickie McDonald. Immunotherapy. 10.2217/imt-2020-0215. Oct 2020.
https://www.futuremedicine.com/doi/10.2217/imt-2020-0215

Current perspectives on the treatment of primary chronic ITP in adults: CME-accredited, independent, virtual symposium – July 2020.
https://cor2ed.com/cme-accredited-independent-virtual-symposium-current-perspectives-on-the-treatment-of-primary-chronic-itp-in-adults/

Raheja et al., 2020: UK Adult Immune Thrombocytopenia (ITP) Pregnancy Registry: Collaborative Research to Better Understand Outcomes: The First 24 Months.
https://onlinelibrary.wiley.com/doi/10.1111/bjh.16638

Full list can be found on our website:
https://www.qmul.ac.uk/itpregistry/latest-news-events-and-links/publications-and-presentations/

REMINDERS

The **recruitment** period in the study has been extended to **30th June 2022** and the new study end date is **30th June 2023**. The baseline data for each patient is from the **date of diagnosis** (not the date of consent) and patients should be followed up until the study end date.

Once a patient has consented to be a part of the study, please send a scanned copy of the consent form(s), along with the updated version of the participants log spreadsheet for your site to the registry inbox, uk-itp.registryteam@nhs.net. Each site will also have to upload the recruitment activity on their local portfolio management system before the end of each month. This will ensure that all recruitment activity for each site is confirmed on the Central Portfolio Management System (CPMS) without any delay.

Below is a table of all the current documents and version numbers that should be in use:

Document Version Date	Version	Date
UKITPR Study Protocol	3.1	03-Aug-20
UKITPR Participant information sheet (PIS)	4.0	06-Jul-20
UKITPR Pregnancy Participant information sheet (PIS)	2.0	06-Jul-20
UKITPR Study Informed Consent Agreement	5.1	03-Aug-20
UKITPR Pregnancy Study Informed Consent Agreement	1.0	16-May-18
UKITPR Invitation letter to participant and remote consenting	1.0	06-Jul-20
UKITPR Invitation letter to participant and remote consenting - Pregnancy registry	1.0	06-Jul-20
GP/consultant information sheets or letters [UKITPR GP letter template]	1.2	16-May-18
Other miscellaneous research delivery documents:		
Document Version Date	Version	Date
Other [Centre Delegation Log]	-	16-May-18
Other [UKITP Registry Data Entry Guide on REDCap Database]	3.1	29-Nov-19
Other [UKITP Pregnancy Registry - REDCap Database - Data Entry Guide]	1.0	29-Aug-18
Other [GP proforma]	1.2	16-May-18
Other [Initial data collection sheet]	2.6	04-Sep-18
Other [Follow up data collection sheet]	2.0	04-Sep-18
Other [Pregnancy Registration Sheet]	1.1	04-Sep-18
Other [Pregnancy status and outcome sheet]	1.1	04-Sep-18

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COMMUNICATIONS

Head over to https://twitter.com/UKITPR and support our Twitter 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/