

Welcome!

Dear all,

Welcome to the latest edition of the UK Adult ITP Registry Newsletter. This edition will focus on recruitment updates, news on the Central Portfolio Management System uploads and some announcements.

16 new sites have joined the study this year and we have over 80 sites actively recruiting and following up patients.

Recruitment:

Our latest recruitment figures as of 23rd August 2019 show that we have recruited 3713 patients. The pregnancy registry has 12 patients recruited so far. A breakdown on the recruitment by each site can be found on the registry website, <http://ukitpregistry.com>.

New sites that have joined in 2019:

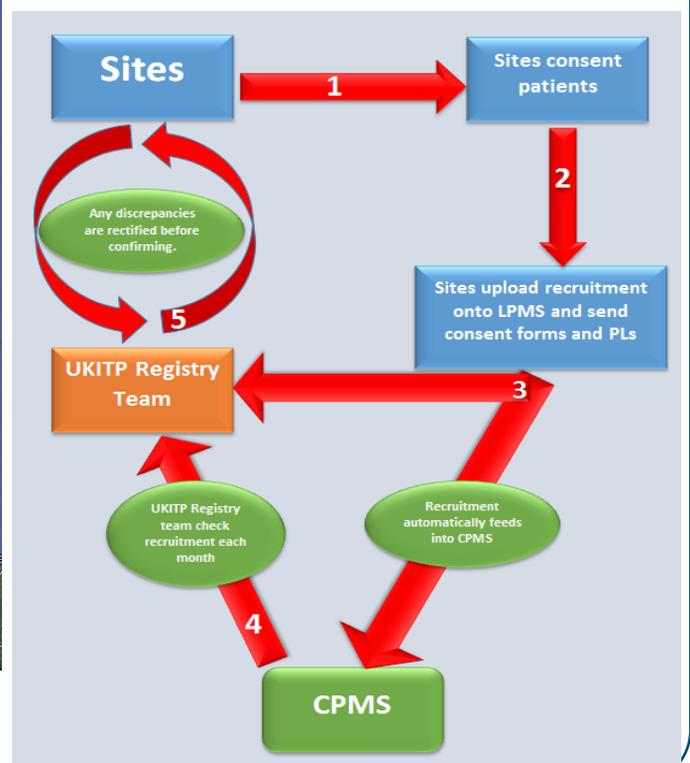
- Epsom & St Helier University Hospitals NHS Trust
- North Bristol NHS Trust
- Sherwood Forest Hospitals NHS Foundation Trust.
- Shrewsbury and Telford Hospital NHS Trust
- South Tyneside NHS Foundation Trust
- Royal Derby Hospital
- Kingston Hospital NHS Foundation Trust
- Kettering General Hospital
- North Cumbria University Hospitals NHS Trust
- Heartlands Hospital
- University Hospital Southampton
- Lewisham & Greenwich NHS Trust
- Birmingham Women's Hospital
- Gloucestershire Hospitals NHS Trust
- Medway Maritime Hospital
- Chesterfield Royal Hospital NHS Foundation Trust

Central Portfolio Management System (CPMS) Uploads

The NIHR has recently changed the reporting of recruitment activity on CPMS. We have circulated this information previously, but as a reminder, the flow chart below depicts the new process.



Map to highlight the spread and locations of all the sites that are actively recruiting and following up patients in the registry.



Data Cleansing

Data cleansing is an ongoing process, however, we will be having a large data gap review and will ask for your co-operation in filling in gaps so we have as complete a data set as possible. We will be asking for data queries via Redcap or email in the coming months.

GP letters and proformas

The GP proforma and 'UKITPR General Practitioner Letter template 1.2' can be used in instances where you do not have a complete medical history (relating to the primary ITP) for a particular patient and so their GP can help to provide any gaps or missing information not present in your own hospital records.

Please note that this is an optional extra tool and is **not mandatory** to be sent for every patient that consents to the registry.

Recent Publications and Presentations

Meeting	Title
Poster presentation, 2019, European Haematology Association (EHA)	Splenectomy in immune thrombocytopenia: do changing treatment patterns for ITP effect outcomes? Data from the UK ITP registry. Todd S et al
Oral presentation, 2018, EHA	Comparison of standard- and low-dose rituximab in Primary Immune Thrombocytopenia (ITP): data from the UK ITP registry. C Gracie et al
Poster presentation, 2018, EHA	Epidemiology and Management of Primary Immune Thrombocytopenia: Real world data from the UK ITP Registry. Zaidi A et al
Oral presentation, 2018, British Society for Haematology (BSH)	Comparison of standard- and low-dose rituximab in Primary Immune Thrombocytopenia (ITP): data from the UK ITP registry. C Gracie et al
Poster presentation, 2018, BSH	Epidemiology and Management of Primary Immune Thrombocytopenia: Real world data from the UK ITP Registry Zaidi A et al

ITP Haematology Nurse Forum

The first ITP Haematology Nurse Forum (Paediatric and Adult) - Moving Beyond the Platelet in ITP, was held in May hosted by Novartis. The meeting was held in London and open nationally to all involved in caring for those with ITP. The feedback from the attendees showed how valuable such a forum is, in expanding current knowledge and practice, sharing knowledge and skills and ensuring we are providing evidence based practice of a high standard.

The forum was an exciting opportunity to meet peers with an interest in ITP and share our knowledge and experience of ITP in both adults and children. The day focus on the treatment options available and the consensus on treatment pathways. To have these forums is an essential component in the care of ITP in allowing professionals to come together who have the same goal for treatment and care.

Collaborations

In May this year, Dr Nichola Cooper (PI at Imperial NHS Foundation Trust) organised and chaired an ITP Assembly. This was sponsored by a number of different pharmaceutical companies and run by Hartley Taylor. The aim of the Assembly was to cover the vast numbers of options for patients with ITP with discussion on how to sequence therapies.

It was an international affair, with talks from Adrian Newland, Jim Bussel, Marc Michel, Donald Arnold, Francesco Zaja and Francesco Rodeghiero. It also included updates from Dave Kuter and Drew Provan on the two revised International and American Society of Hematology ITP guidelines, which are due to be published this year and updates from Vickie McDonald, John Grainger, Quentin Hill and Charlotte Bradbury from the UK ITP registries, the UK ITP forum, and the recently completed FLIGHT study.

It was an exciting and well-attended event. They will be planning a similar event in May 2020.

Manchester University NHS Foundation Trust will be holding an **ITP Study Day** on Friday 20th September 2019 at the Manchester Cathedral Visitor Centre, Victoria Street, Manchester, M3 1SX. **Please contact Claire for bookings on 01617018416.** Below is the agenda for the day:



Manchester
Cathedral

NHS

Manchester University
NHS Foundation Trust



Morning Session Physicians and Nurses:

- 09:30 Registration and Coffee for morning session
- 09:45 – 10:30 Lecture 1 – Diagnosis of ITP (Dr Jecko Thachil)
- 10:30 – 11:15 Lecture 2 – Pivotal ITP research (Dr John Grainger)
- 11:15 – 11:30 Coffee break
- 11:45 – 12:30 Lecture 3 - New ASH and International guidelines for children and Adults (Dr John Grainger)
- 12:30 – 13:00 Q & A
- 13:00 – 14:00 Lunch and departure of morning guests

Afternoon Session Families:

- 13:45 Registration and Coffee for afternoon session
- 14:00 – 14:40 Lecture 4 – How do I know it is ITP (Dr Jecko Thachil)
- 14:40 – 15:20 Lecture 5 – Treatment of acute bleeding (Dr John Grainger and adult nurse)
- 15:20 – 15:45 Coffee break
- 15:45 – 16:15 Lecture 6 – Treatment of persistent ITP (Dr John Grainger and Rachael McDermott)
- 16:15 – 16:45 Q& A
- Close

ITP Support Association Local Group Meetings

The ITP support Association are organising a number of local ITP group meetings around the country. These local groups are an opportunity for ITP patients, their family and friends to meet in an informal setting giving them an opportunity to chat and talk about each other's experiences with ITP. If you are interested in supporting a local group meeting, please contact Mervyn Morgan via mervyn@itpsupport.org.uk.

Further information and upcoming dates for the local group meetings can be found on the link below:

<https://www.itpsupport.org.uk/index.php/en/itp-local-group-meetings>

Haematology Nurses Day

The Royal London Hospital ITP Centre will be running a 2 day Nurses ITP Course. This will be held in Early 2020. For information please contact Louise Taylor via l.taylor6@nhs.net

