

Welcome!

Hello and welcome to the latest issue of the UK Adult ITP Registry newsletter! Thank you to everyone for their ongoing support and work on the registry.

Study Updates

Before the Christmas break, we submitted a request to the HRA to bring the study under complete HRA approval. Since this was a pre-HRA study, we never had complete HRA approval and so we were unable to add any new sites. The HRA assessment is complete now and we have permission to add new sites to the registry. We are in the process of setting up over 15 new sites to join the study and we have already got confirmation of capacity and capability from 6 sites. We'd like to welcome the teams from:

- 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

We wish the new sites all the best in their recruitment and hopefully the surge of new sites will help us boost the accruals in the coming year.

Pregnancy Registry

As you are all aware, we have extended the study recruitment to patients who are pregnant with primary ITP. This will help further our understanding of management of patients with primary ITP during pregnancy and provide information on best management practices. We have recruited 6 patients to this arm of the study already! Thank you to all those who have contributed.

Reminders

We still have a hold on the blood sample aspect of the study and so sites do not have to collect blood samples from patients. We are working to process our current backlog and will notify all sites when this is complete and when we can re-start receiving blood samples from sites.

Please send through updated participants logs and consent forms to us when you recruit any new patients. This will enable us to upload the latest recruitment figures onto the Central Portfolio Management System, thereby ensuring your activity is reported to NIHR in a timely manner.

If there are any changes to your local research team, please send through updated delegations logs and if applicable, the relevant research CVs and GCP certificates.

For pregnant patients, please remember to consent the patient to the main adult registry and the pregnancy registry as well.

Upcoming Events

ITP Assembly – Update Day

Thursday 9th May 2019
Cavendish Conference Centre, 22 Duchess Mews, London W1G 9DT

Please see attached flyer with the event and registration details. Contact Alex Slade from Hartley Taylor for further information.

To register online please visit
www.hartleytaylor.co.uk
Enquiries: alex@hartleytaylor.co.uk or
Telephone: 01565 621967

Recruitment Update

As of 12/03/2019, we have 3473 patients consented to the registry. Below is a table with the 25 sites who have recruited the highest number of patients.

	Hospital	Number consented
1	THE ROYAL LONDON HOSPITAL	298
2	UNIVERSITY COLLEGE HOSPITAL	160
3	HAMMERSMITH HOSPITAL	151
4	THE ROYAL VICTORIA INFIRMARY	130
5	SUNDERLAND ROYAL HOSPITAL	130
6	CASTLE HILL HOSPITAL	110
7	KENT & CANTERBURY HOSPITAL	102
8	NORTHWICK PARK HOSPITAL	94
9	GLASGOW ROYAL INFIRMARY	84
10	QUEEN ALEXANDRA HOSPITAL	79
11	THE ROYAL LIVERPOOL UNIVERSITY HOSPITAL	77
12	CHURCHILL HOSPITAL	74
13	BRADFORD ROYAL INFIRMARY	71
14	LEICESTER ROYAL INFIRMARY	68
15	ROYAL CORNWALL HOSPITAL (TRELISKE)	68
16	LUTON & DUNSTABLE HOSPITAL	65
17	ST JAMES'S UNIVERSITY HOSPITAL	63
18	QUEEN'S HOSPITAL	62
19	NORTH TYNESIDE GENERAL HOSPITAL	62
20	PRINCESS ROYAL UNIVERSITY HOSPITAL	57
21	WORCESTERSHIRE ROYAL HOSPITAL	56
22	NEVILL HALL HOSPITAL	54
23	HARROGATE DISTRICT HOSPITAL	54
24	UNIVERSITY HOSPITAL OF WALES	50
25	WEST MIDDLESEX UNIVERSITY HOSPITAL	46

We appreciate the effort from all sites and a full list of sites and recruitment can be found on our website.

UK ITP Registry Contact Details

Royal London Hospital
2nd Floor Pathology & Pharmacy Building
80 Newark Street
Whitechapel
London, E1 2ES

New Direct Telephone No.: 0203 246 0473
Email: UK-ITP.registryteam@nhs.net

The UKITP Registry Website

For the latest updates and developments with the ITP Registry, be sure to visit the UKITP Registry website on <http://ukitpregistry.com>.

You'll also be able to download all the trial documents (current and previous versions); user guides, proformas for the REDCap database and much, much more.