

UK Adult ITP Registry

NEWSLETTER

MARCH 2018



In this particular issue of our newsletter we want to inform you about all the change that has been going on here at the registry.

Thank You

We must start this newsletter by saying a huge THANK YOU to all of you who work alongside us. It has been a busy two years since the last newsletter with lots of change here at the registry. We are grateful for the ongoing support from all our sites.

What's been happening?

The UK ITP Registry moved to REDCap

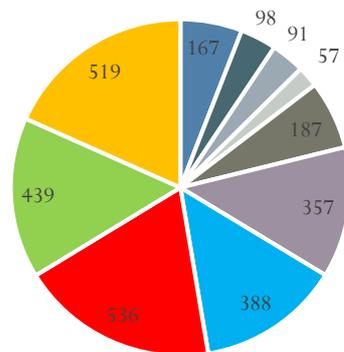
We have now completed the transition to REDCap as our database repository.

REDCap has more streamlined functions for data control and analysis with built-in quality assessment tools allowing us to get the best data possible.

We appreciate the move to the new database has been time consuming and a learning curve and we thank you for your patience.

Links to the quick user guide for the latest version can be found on the ITP registry website and in the 'file repository' section on REDCap itself.

no. of participants



■ 2007 ■ 2008 ■ 2009 ■ 2010 ■ 2011
■ 2012 ■ 2013 ■ 2014 ■ 2015 ■ 2016

Recruitment Update

We now have more than 80 sites and over 3000 adult patient registered. Please make sure you send us all new consent forms before the end of March so we can amend the NIHR figures.

Welcome to Dr Vickie McDonald

As you all know, Drew Provan retired at the end of August and we have been working hard to recruit a new consultant to take on the leadership of The UK ITP Registry. We are really pleased to be able to announce Dr Vickie McDonald started here with us in September 2017. Dr McDonald will be taking over as CI in the next coming months.



Update on the current registry team

The current ITP Registry team are:

Dr Vickie McDonald- Current PI at the Royal London and will take over as CI for the registry formally in the coming months

Dr Dan Hart- Interim CI

Prof Adrian Newland- Professor of haematology

Dr Drew Provan- Lecturer in haematology and honorary consultant Haematologist

Louise Taylor- Senior Clinical and Research Nurse Specialist

Dr Abbas Zaidi- Research Fellow

Caitlin Gracie- Data Manager

Atiqah Miah- Data Manager

If you need to get in touch, please contact us using the following details.

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Blood Samples

We are not currently accepting blood samples as we have reached our storage capacity. We are currently trialing automating DNA extraction. Once this process is established we will extract all the samples we currently hold and will start taking new samples again. We anticipate that this process will be up and running during 2018. Thank you for your patience. We will be in touch as soon as we are ready for samples again.

A Fond Farewell

We wish our Senior Epidemiologist, Umesh Doobaree, all the best with his future work and projects and want to say a big thank you for the last five years spent here at the registry.

Raghava Nandigam, our previous Data Manager has been assisting us with some work over the last few months however also moves on to new projects – good luck Raghava

Publications

Below is a selection of publications from the team:

Thromboembolism in adults with primary immune thrombocytopenia: a systematic literature review and meta-analysis. Doobaree IU, Nandigam R, Bennett D, Newland A, Provan D. *Eur J Haematol.* 2016 Oct;97(4):321-30

Fostamatinib in persistent/chronic adult immune thrombocytopenia. Newland A, Lee EJ, McDonald V, Bussell JB. *Immunotherapy.* 2018 Jan;10(1):9-25

Safety and efficacy of romiplostim in splenectomized and nonsplenectomized patients with primary immune thrombocytopenia. Cines DB, Wasser J, Rodeghiero F, Chong BH, Steurer M, Provan D, Lyons R, Garcia-Chavez J, Carpenter N, Wang X, Eisen M. *Haematologica.* 2017 Aug;102(8):1342-1351

Guidelines on the management of drug-induced immune and secondary autoimmune, haemolytic anaemia Quentin Hill, Robert Stamps, Edwin Massey, John Grainger, Drew Provan and Anita Hill, *Brit J Haematol*, 2017, 177, 208-220

Case report of eltrombopag in a pregnant patient with ITP KLM White, L Bowles, D Provan, L Taylor, A Newland *BSH*, 2017

Comparison of the effects of the TPO receptor agonist, Romiplostim, in patients with ITP < 1yr versus > 1yr. DJ Kuter, AC Newland, BH Chong, F Rodeghiero, MT Romero, I Pabinger, Y Chen, B Metha, M Eisen *ASH 2017; BLOOD 2017, 130, 1055*



The UK ITP Registry team

Presentations at national and international meetings in 2017

British Society Haematology 2018

Comparison of standard- and low-dose rituximab in Primary Immune Thrombocytopenia (ITP): data from the UK ITP registry. -C Gracie², A Zaidi¹, U Doobaree², L Taylor¹, D Provan², A Newland², V McDonald¹

American Society Haematology, Dec-17

Treatment, platelet count pattern and comorbidities among primary immune thrombocytopenia (ITP) patients seen in routine clinical practice: data from the United Kingdom Adult Immune Thrombocytopenia (UK ITP) Registry. -Umesh Doobaree, Lara Wyatt, Raghava Nandigam, Adrian Newland, Drew Provan

British Society Haematology, 2017

Primary Immune Thrombocytopenia in Great Britain: Epidemiology and Service Utilisation. -Umesh Doobaree, Katherine Conway, Raghava Nandigam, Adrian Newland, Drew Provan

The United Kingdom Immune Thrombocytopenia Registry: an update and treatment pattern description over time. -Umesh Doobaree, Sam Hodges, Ella Ramseyer-Bache, Raghava Nandigam, Rebecca Frances, Lara Wyatt, Adrian Newland, Drew Provan

European Haematology Association, 2017

Primary Immune Thrombocytopenia Treated with Romiplostim in Routine Clinical Practice: A Retrospective Study from the United Kingdom Immune Thrombocytopenia Registry.

-Umesh Doobaree, Raghava Nandigam, Lesley Mensah, Anouchka Seesaghur, Hitan Patel, Sally Wetten, Drew Provan

Bleeding in primary immune thrombocytopenia: who are most at risk? -Umesh Doobaree, Samantha Hodges, Raghava Nandigam, Adrian Newland, Drew Provan

Primary ITP in adults treated with eltrombopag: a retrospective study using data from the United Kingdom adult immune thrombocytopenia registry. -Umesh Doobaree, Adrian Newland, John Fleming, Drew Provan

Projects and collaborations

We are pleased to announce that Dr Quentin Hill was awarded a grant from the BMA to look at FcR receptor mutations in ITP with his team in Leeds in collaboration with the UK ITP registry. This will run over several years and we hope will give us further insight into treatment responses in ITP

News from the ITP forum

The UK ITP Forum is a working group of health care professionals with an interest in the care of patients with immune thrombocytopenia (ITP). At time of writing, it is great to see a survey of forum members approach to the use of thrombopoietin receptor

agonists (TPO-RA), led by Dr Jecko Thachil, published in the current issue of the British Journal of Haematology. It is hoped that this will provide some guidance to clinicians managing problems such as how to titrate these drugs, how to deal with wide platelet count swings and when to consider stopping therapy. For clinicians that would like to use a written plan to help guide ITP directed interventions around surgery, an ITP specific, perioperative template can be downloaded from the forum website

at <http://www.ukitpforum.org/guidelines.htm>. As we speak, UK ITP clinical centres (centres able to accept referrals regarding complex or difficult cases of ITP) are undergoing their first national audit. Most centres are participating in the FLIGHT study comparing up front mycophenolate with steroid vs. steroid alone while a number are also participating in commercial studies of novel agents. The forum website has a map showing where to find the local ITP clinical centre so get in touch with them if you are interested in referring patients for clinical studies. There has been widespread uptake of TPO-RA drugs, the first licensed treatment for ITP, and updated ITP treatment guidelines from the American Society of Hematology (in process) and the International Consensus group are anticipated. The forum will next meet at the BSH Scientific Meeting in Liverpool, April 2018.