

Paediatric Working Party

Membership

Dr Mary Mathias	Chair, London (GOSH)
Dr Jeanette Payne	Secretary, Sheffield
Dr Jayanthi Alamelu	London (Evelina)
Dr Neha Bhatnagar	Oxford
Dr Tina Biss	Newcastle
Dr Elizabeth Chalmers	Glasgow
Dr John Grainger	Manchester
Dr Simone Greene	Hull
Dr Anne Kelly	Addenbrookes
Dr Jayashree Motwani	Birmingham
Dr Mike Richards	Leeds (outgoing)
Dr Simone Stockley	Nottingham
Dr Oliver Tunstall	Bristol (outgoing)

The working party membership was renewed in October 2020.

Meetings

Since the last AGM the PWP has held 3 teleconference or virtual meetings.

Summary of activities

Immune Tolerance Induction (ITI) consensus update post emicizumab commissioning.

This was developed in conjunction with the Inhibitor Working Party and has now been submitted for publication to Haemophilia and will be available on the UKHCDO website.

ITI outcomes

ITI outcome data using the previous UKHCDO ITI protocol was presented at the UKHCDO Education meeting in 2018. Data collection was from 2015 to Dec 2019. This data is now being analysed but this will be time consuming due to presentation and need to data clarify.

Emicizumab PUP and MTP data

Given the delay in starting the NHD PUP registry data collection caused by the enquiry, the Chair asked the NHD to request a 'snap-shot' of data on use of emicizumab in children under 12 years with and without inhibitors. This has been collated by Liz Chalmers and will be submitted as an abstract for EAHAD 2021. No children under 4 months have received emicizumab. There is considerable centre variation in the use of emicizumab for non-inhibitor children.

A National Advisory Group/MDT

This has now been established with 3 monthly teleconferences with terms of reference for discussion and recording of outcome. Calls for cases to discuss are sent out to paediatric treating centres prior to the dates with a data pro forma.

Other projects

Data collection has inevitably been delayed by the COVID epidemic and prior to that by uncertainty around the NHD research database in terms of requirement for consent. We will now continue to pursue:

- a. PUP registry- a template for data collection has been created within the NHD with the plan to ask for data to be collected every 3 months
- b. Inhibitors in Haemophilia B.
- c. Outcomes and prophylaxis in Moderate Haemophilia A and B.
- d. Bleeding and treatment in children with rare coagulation disorders starting with severe FVII deficiency.

Dr Mary Mathias
Chair, Paediatric Working Party
October 2020