

Paediatric Working Party

Membership

Dr Elizabeth Chalmers	Chair, Glasgow
Dr Jeanette Payne	Secretary, Sheffield
Dr Jayanthi Alamelu	London (Evelina)
Dr Neha Bhatnagar	Oxford
Dr Tina Biss	Newcastle
Dr Mary Mathias	London (GOSH)
Dr Jayashree Motwani	Birmingham
Dr Mike Richards	Leeds
Dr Oliver Tunstall	Bristol

The working party membership was renewed in October 2017.

Meetings

Since the last AGM the Paediatric Working Party (PWP) has held 1 face to face meeting and 4 teleconferences.

Recent meetings have facilitated discussion regarding the introduction of Emicizumab for non-inhibitor patients.

Summary of activities

1. Immune Tolerance Induction (ITI) protocol update

A standard ITI protocol based on the UKHCDO Guideline was agreed and commissioned previously and has been in use since 2015. This protocol is currently being updated to include the use of Emicizumab. This piece of work is being undertaken in collaboration with the inhibitor working party. A final draft is expected to be available for circulation shortly.

2. ITI outcomes

ITI outcome data using the current UKHCDO ITI protocol was presented at the UKHCDO Education meeting in 2018. Data collection has continued during this year. Once the current ITI protocol has been revised and approved a final analysis of outcomes using the previous protocol will be produced.

3. Intra-cranial haemorrhage

Retrospective data collection (2003-2015) on cases of intracranial haemorrhage (ICH) occurring in children <16yrs of age in the UK has been completed and has been published in the journal *Haemophilia*. Data collection is ongoing as part of the adverse event reporting and we would encourage reporting of these events.

4. Now that the NHD Research Data base has been approved the working party will continue to work on data collection/analysis in relation to the following topics:

- a. PUP registry
- b. Inhibitors in Haemophilia B.
- c. Outcomes in Moderate Haemophilia.
- d. Bleeding and treatment in children with rare coagulation disorders.

5. A national advisory group/MDT which will aim to act as a forum for advice on the management of children with complex problems related to inherited bleeding disorders will be launched at the beginning of next year.

Dr Elizabeth Chalmers
Chair, Paediatric Working Party
October 2019