

Paediatric Working Party

Membership

Elizabeth Chalmers	Chair	Glasgow
Jeanette Payne	Secretary	Sheffield
Mike Williams		Birmingham
Mary Mathias		GOSH, London
Mike Richards		Leeds
Peter Collins		Cardiff
Jayanthi Alamelu		Evelina, London
Oliver Tunstall		Bristol

Working Party timeline: due to complete current term October 2016.

Meetings

Two per annum with additional telecoms as required.

Summary of current activities

1. Follow up of Immune tolerance therapy in the UK

Retrospective outcome data on the results of immune tolerance therapy in the UK (2003-2015 inclusive) has been collected from 8 UK CCCs treating children with inhibitors. Initial results were presented at the ISTH meeting in 2015. This has now been updated to include data up to the end of 2015. Results of this analysis will be presented at the AGM meeting & a manuscript is being prepared for publication. The results highlight variation in outcomes in different ethnic groups and the results of second & third line ITI.

2. Management & outcome of Immune tolerance using a standardised regimen - ongoing data collection in collaboration with the Inhibitor Working Party

A standard ITI protocol has been agreed based on the published UKHCDO Guideline on management of inhibitors. New inhibitors are reported to the NHD and prospective data collection on ITI outcomes is now being collected.

3. Intracranial haemorrhage in inherited bleeding disorders

Retrospective data collection (2003-2015) on cases of ICH occurring in children <16yrs of age in the UK has been completed. Initial data was presented at the ISTH meeting in 2015. This has now been updated and the results will be presented at the AGM meeting. The data highlight the continuing risk of this complication in very young children with severe bleeding disorders.

Prospectively data collection on ICH in both children and adults has been added to the NHD adverse events reporting scheme.

4. Audit of prophylaxis in haemophilia against current BCSH/UKHCDO Guideline

Data collection is complete. Baseline data has been collected from all centres relating to the use of prophylaxis in children. More detailed information on the use of prophylaxis has been collected from CCCs represented on the WP. The results were presented at the ISTH previously and the intention is to submit a short manuscript on the findings.

5. Use of subcutaneous DDAVP in children with haemophilia and vWD

Results are currently being collated.

Guidelines

This working party is responsible for two current BCSH/UKHCDO guidelines:

1. Prophylaxis in children with haemophilia A. Published 2010

This guideline is now > 5yrs old and is due for review.

2. Management of haemophilia in the fetus and newborn. Published 2011

It is envisaged that much of the content of this guideline will be incorporated into the RCOG/UKHCDO guideline on the management of pregnancy in women with inherited bleeding disorders which is currently in preparation. The current guideline will be reviewed following completion of the RCOG guideline and a decision will then be made on the need for a separate guideline covering neonatal issues.

The Working Party also regularly reviews new guidelines in order to discuss their impact on paediatric practice.

Presentations/publications

PROPHYLAXIS IN CHILDREN WITH SEVERE AND MODERATE HAEMOPHILIA: A SURVEY OF UK PRACTICE. Ryan Rodgers*¹, Jay Alamelu², Peter Collins³, Mary Mathias⁴, Jeanette Payne⁵, Mike Richards⁶, Oliver Tunstall⁷, Mike Williams⁸, David Young⁹, Tina Biss¹⁰, Angela Thomas¹¹, Elizabeth Chalmers¹ on behalf of On behalf of the Paediatric Working Party of UKHCDO. Journal of Thromb Haemostas 2015; Vol 13 S2: OR10

ITI FOR INHIBITORY ANTIBODIES IN BOYS WITH SEVERE HAEMOPHILIA A AT EIGHT UK CHILDREN'S CENTRES 2003-2013 Mary Mathias*¹, Jayanthi Alamelu², Peter Collins³, Jeanette Payne⁴, Mike Richards⁵, Oliver Tunstall⁶, Mike Williams⁷, Tina Biss⁸, Elizabeth Chalmers⁹. Journal of Thromb Haemostas 2015; Vol 13 S2: OR145

INTRACRANIAL HAEMORRHAGE IN CHILDREN WITH INHERITED BLEEDING DISORDERS IN THE UK 2003-2013. Elizabeth Chalmers*¹, Jayanthi Alamelu², Peter Collins³, Mary Mathias⁴, Jeanette Payne⁵, Mike Richards⁶, Oliver Tunstall⁷, Mike Williams⁸, Ben Palmer⁹, Andrew Mumford¹⁰ on behalf of On behalf of the Paediatric and Rare Disorders Working Parties of UKHCDO. Journal of Thromb Haemostas 2015; Vol 13 S2: OR386

Dr Elizabeth Chalmers
Chairman, Paediatric Working Party
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