

Paediatric Working Party

Membership

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

Working Party timeline: extended to Oct 2016 to complete existing work.

Meetings

Meetings 2015 – 1 face to face meeting, 2 WebEx/telecom meetings.

Summary of current activities

1. Follow up of Immune tolerance therapy in the UK

Retrospective data on the outcome of immune tolerance (2003-2013 inclusive) has been collected from 8 UK CCCs treating children with inhibitors. Results were presented at the ISTH meeting in June. This study has generated useful data on the outcomes in different ethnic groups and on the results of second & third line ITI. The data is currently being updated and will then be submitted for publication.

2. Management & outcome of Immune tolerance using a standardised regimen - ongoing in collaboration with IWP

A standard ITI protocol has been agreed previously and was updated in Sept 2015. Data collection and outcome of ITI will be collected prospectively from all CCCs undertaking ITI in children. New inhibitors and results of ITI will be reported to the NHD.

3. Intracranial haemorrhage in inherited bleeding disorders

Retrospective data collection has been completed (2003-2013). 55 cases were reported and the initial data was presented at the ISTH meeting in June. The survey is currently being updated. Prospectively data collection on ICH will be added to UKHCDO adverse event reporting.

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 meeting in June.

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

Results are currently being collated.

Guidelines

This WP is responsible for 2 current BCSH/UKHCDO guidelines -

1. 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.

2. Prophylaxis in children with haemophilia A. Published 2010

No immediate requirement for update but will require review/update following introduction of the new extended half-life products.

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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