

Inhibitor Working Party

Membership

Dan Hart	Chair
Kate Talks	Secretary
Trevor Baglin	
Liz Chalmers	
Peter Collins	
Charles Hay	
Ri Liesner	
Mike Makris	
Ben Palmer	
Savita Rangarajan	
Anne Riddell	
Olly Tunstall	
Mike Williams	

Meetings

The working party was reconstituted in the autumn of 2014 and we have met face to face 3 times since, with 2 teleconferences.

Activities

Since the publication of the UK-PUP data ⁽¹⁾ there has been an ongoing dialogue with the European Medicines Agency (EMA), Pednet & Francecoag investigators to agree and implement a meta-analysis of all available data pertaining to the question of brand specific PUP inhibitor risk. This independent analysis is being undertaken by colleagues at the Paul Ehrlich institute, Germany, appointed by the EMA, and is now underway. As a group, the Inhibitor Working Party will now perform annual interim analyses of NHD registry data to look for signals of inhibitor risk with the ever maturing data set. Given a further 3 years have elapsed since the conclusion of the UK-PUP cohort, we intend to optimize this data set to match that reported in our published cohort ⁽¹⁾ and make this available to the EMA if required.

As a result of the requirements of the EMA investigation, the quality of submitted data to the NHD registry has been a focus of our attention, particularly of the PUP cohort. After discussions in both inhibitor and paediatric working parties, we want to explore ways to facilitate data returning from paediatric centres to enable more responsive monitoring of inhibitor risk as part of our safety/surveillance remit. The paediatric and inhibitor working party proposals for this will be presented at the AGM, anticipating the requirement for closer audit in the next round of UKHCDO Triennial reviews, particularly PUP exposure data, inhibitor occurrence and ITI treatment data.

The working party has prompted further review of the stalled NHS England ITI commissioning document with a view to getting final agreement. We would hope to submit the proposed revision at the AGM.

Subsequent to the published UKHCDO initiated survey of UK practice in treating acquired haemophilia A ⁽²⁾, we are in the early stages of exploring the possibility of a collaborative, prospective national study with German and Austrian colleagues to address the uncertainties about strategies of immunosuppression.

Anne Riddel has joined the WP representing haemostasis biomedical scientists. She is currently working to establish links with laboratory leads in UK comprehensive and treatment centre laboratories to survey variation in laboratory practice and enhance subsequent communication. Please liaise with your laboratory leads about this to optimise responses to this survey, which should then report early in 2016.

Finally, I would like to express our gratitude as UKHCDO members to Professor Peter Collins for his very effective leadership and hard work in the role of chair of this group, as well as to NHD colleagues who have facilitated the publication of our cohorts ^(1, 3) that have contributed important data to the international haemophilia community.

Publications

1. Factor VIII brand and the incidence of factor VIII inhibitors in previously untreated UK children with severe hemophilia A, 2000-2011.
Collins PW, Palmer BP, Chalmers EA, Hart DP, Liesner R, Rangarajan S, Talks K, Williams M, Hay CR; UK Haemophilia Centre Doctors' Organization.
Blood. 2014 Nov 27;124(23):3389-97. doi: 10.1182/blood-2014-07-580498.
2. A national survey of immunosuppression strategies for acquired haemophilia A.
Batty P, Palmer B, Chalmers E, Hay CR, Liesner R, Rangarajan S, Talks K, Williams M, Collins P, Hart DP.
Haemophilia. 2015 Jan;21(1):e73-6. doi: 10.1111/hae.12547.
3. The incidence of factor VIII inhibitors in severe haemophilia A following a major switch from full-length to B-domain-deleted factor VIII: a prospective cohort comparison.
Hay CR, Palmer BP, Chalmers EA, Hart DP, Liesner R, Rangarajan S, Talks K, Williams M, Collins PW.
Haemophilia. 2015 Mar;21(2):219-26. doi: 10.1111/hae.12563.

Dr Dan Hart,
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