

Inhibitor Working Party now dissolved

Membership

Dr Dan Hart	Chair
Dr Kate Talks	Secretary

Prof Peter Collins
Dr Georgina Hall
Prof Charles Hay
Dr Ri Liesner
Prof Mike Makris
Ben Palmer
Dr Charles Percy
Dr Anne Riddell

The Inhibitor working party (IWP) met virtually in Q1 of 2020 to conclude this cycle of work under Dan Hart's chairmanship. The group was then dissolved and will be reconstituted with Charles Percy as chair.

Anne Riddell continued to facilitate communication with all Comprehensive care centre (CCC) laboratory chiefs, monitoring their new assay development and availability for Bethesda assays whilst on Emicizumab; chromogenic FVIII assays with human or bovine reagents and porcine FVIII (Obizur®) inhibitor assays. Upon request, this data repository remains available to colleagues, needing access to assays or technical advice. The direct communication between the IWP and CCC laboratory staff has been an important step forward in recent years as we enter a more challenging landscape of laboratory monitoring for different therapeutics. A collaborative project with NEQAS highlights the ongoing variability between comprehensive care centres in their standard inhibitor assay practices. This was recently accepted for publication by Haemophilia journal.¹ Ongoing dialogue between labs will be an important support to minimize further methodological variability as more assays emerge.

Acquired Haemophilia A enhanced data collection has concluded after 4 years of prospectively collected data. Analysis will commence in early 2021 after all patients have completed 12 months follow up. This will be overseen by Charles Percy and Dan Hart. A snapshot of Obizur® use in the first 18 months after NHS England commissioning approval is also underway in collaboration with NHS England.

Indications for Emicizumab continued to be a significant workstream. Georgina Hall and Liz Chalmers head the continuing prospective collection of Immune Tolerance Induction (ITI) data. Revised guidance for ITI has been agreed between the IWP and Paediatric Working party². This revision of ITI guidance incorporates the option to use the bi-phenotypic antibody, Emicizumab, as a prophylaxis haemostatic agent to reduce bleeding rates and to facilitate low dose and reduced frequency of FVIII CFC for ITI in the majority of children. The consensus being FVIII ITI remains the gold standard for a newly detected inhibitor with an expectation that upon tolerisation FVIII concentrate would remain the preferred prophylaxis agent thereafter. For those failing ITI, Emicizumab would be the preferred prophylaxis agent.

I wish to thank all the working party and NHD staff for their hard work, support and enthusiasm during the last cycle of activity whilst I was chair. I wish Charles Percy well as he takes over as chair of this working party.

Publications

- 1 Factor VIII/IX Inhibitor Testing Practices in the United Kingdom: Results of a UKHCDO and UKNEQAS National Survey
Batty P, Riddell A, Kitchen S, Sardo Infirri S, Walker I, Woods T, Jennings I, Hart DP
Accepted for publication in Haemophilia
- 2 Immune tolerance induction in severe haemophilia A: A UKHCDO inhibitor and paediatric working party consensus update.
Hart DP, Alamelu J, Bhatnagar N, Biss T, Collins PW, Hall G, Hay CR, Liesner R, Makris M, Mathias M, Motwani J, Palmer B, Payne J, Percy C, Richards M, Riddell A, Talks K, Tunstall O, Chalmers EA
Submitted for publication in Haemophilia

Dr Dan Hart
Outgoing Chair, Inhibitor Working Party
October 2020

Inhibitor Working Party reconstituted

The Inhibitor Working Party has recently been re-constituted with the following membership:

Membership

Dr Charles Percy	Chair
Dr John Grainger	
Dr Dan Hart	
Prof Mike Makris	
Dr Mary Mathias	
Ben Palmer	
Dr Anne Riddell	
Dr Kate Talks	

The group have yet to meet but a date is the process of being finalised. The initial priorities are to review and update relevant guidelines, particularly relating to the management of acquired coagulation inhibitors.

Dr Charles Percy
Chair, Inhibitor Working Party
October 2020