Inhibitor Working Party

Membership

Dr Dan Hart	Chair
Dr Kate Talks	Secretary
Dr Elizabeth Chalmers	
Prof Peter Collins	
Dr Georgina Hall	
Prof Charlie Hay	
Dr Ri Liesner	
Prof Mike Makris	
Ben Palmer	
Dr Charles Percy	
Dr Anne Riddell	

The Inhibitor Working Party (IWP) has been reconstituted and welcomed new membership. We have met twice face to face, a third time via a comprehensive teleconference call and multiple ad hoc communications to address the important issues emerging in this rapidly changing field.

IWP members led or contributed to clinical policy development for both recombinant porcine FVIII (susoctocog alpha, Obizur®, Shire) and biphenotypic FVIII-mimic antibody (Emicizumab, Hemlibra®, Roche). These have both now been NHS England approved for acquired haemophilia A (AHA) and congenital haemophilia A with inhibitors respectively and also adopted in devolved nations. Our laboratory survey and subsequent updates for the availability of the product specific assays identified the initial variation in availability of assays between centres, but importantly provided a document for centres' labs to identify which neighbouring laboratories could perform these urgently if needed. Our laboratory specific email cascade has facilitated direct communication between NHD and lab chiefs and between labs in this key time of rapid change.

Obizur use in AHA has been included in the continuing national prospective data collection in AHA. This prospective data collection has entered its 3rd year and collected data on treatment and 12 months outcomes for over 300 AHA patients.

The launch of the early access scheme for Emicizumab in January 2018 required rapid generation of national guidance to treat bleeds in the presence of Emicizumab. These guidelines have been openly accessible via the Haemophilia journal since early in the year and remain a key reference document for treaters internationally. Our ongoing prospective collection of ITI outcome data is now integrating Emicizumab use as we continue to understand how to position this molecule in routine clinical care. Future NHD data will be crucial to inform this ongoing debate about the importance of long-term tolerance to FVIII. IWP members have had multiple discussions with various stakeholders to safeguard control and oversight of emerging data, whilst looking to find

ways of working productively with other registries, either as product specific registries (e.g. Emicizumab) or in the European Medicines Agency future registries initiative.

IWP and NHD team members have endeavoured to ensure clarification and rapid communication to the membership of any product specific adverse events and intend to launch an NHD, Emicizumab-specific prospective data collection (analogous to the AHA system) at the annual general meeting.

The past year has seen unprecedented change in the field of inhibitor therapeutics, laboratory monitoring and treatment algorithms. I am very grateful to the entire IWP membership who have all contributed to a much more fluid and demanding need than ever before to respond to events as they have emerged. Also, on behalf of the IWP membership, we would like to express our gratitude to all centres for their ongoing data returning for the multiple initiatives.

Dr D Hart
Chair, Inhibitor Working Party
October 2018