

Co-Morbidities Working Party

Membership

Chair

Dr Susie Shapiro, Oxford

UKHCDO representatives:

Dr Gary Benson, Belfast

Dr Gillian Evans, Canterbury

Dr Rhona Maclean, Sheffield

Dr Sarah Mangles, Basingstoke

Prof Mike Makris, EUHASS

Prof Charles Hay, NHD (member until April 2021)

Haemophilia Nurses

Association Representative:

Cathy Harrison, Sheffield

Remit

To consider comorbidity issues in patients with bleeding disorders within the UK and review any unmet need with respect to data collection, guidelines and patient related information / material.

To develop a Work Plan for the CMWP.

To advise the DMWP as to what data the NHD should collect regarding comorbidities in patients with haemophilia and bleeding disorders.

Any publications arising from the CMWP should be approved by the UKHCDO Executive in line with the UKHCDO publication policy.

Additional remit Jan 2020 - April 2021: To review reported adverse events of special interest potentially related to products (including thrombotic events, mortality, allergy): to agree consensus on severity and outcome of event and evaluate any potential relationship to treatment

Meetings

We held monthly online video meetings in order to review new adverse events of special interest related to any product (as well as reviewing historical events reported with Emicizumab) until April 2021; and then have continued almost monthly meetings in order to progress further Work Plan.

Activities

1. Adverse events of special interest (until April 2021).
 - a. Agreed process for reviewing adverse events of special interest, including SOP and new forms to request additional information via NHD. The decision with regards to causality and relationship to product required minimum of 3 members of the group to be present. All relevant historic reported events on emicizumab were reviewed and the group kept up to date with newly reported events (any product). The consensus decision of reported events was included in the annual report and any serious adverse events feedback rapidly to UKHCDO membership.

- b. At the last AGM 2020 there was agreement that a group should be established to review all serious adverse events and the Exec and NHD decided that this would be best served by an 'NHD Adverse Events Panel' rather than a Working Party; with the new groups membership to include NHD co-directors Chair of DMWP, EUHASS rep, inhibitor/paediatric/CMWP representatives and an HNA representative. CMWP was supportive of this proposal and the NHD Adverse Events Panel was established in May 2021. Following this change in remit for CMWP, Prof Charles Hay left the working party in order to Co-Chair the Adverse Events Panel. We would like to thank Prof Hay for his contribution to CMWP and his support in reviewing adverse events of special interest.

2. Cardiovascular disease and bleeding disorders.

The group agreed to write an up-to-date review on cardiovascular disease in patients with haemophilia (prevalence and management) in order to highlight areas of unmet need/lack of data and potential areas for future data collection/research/service improvement. The review is close to being submitted, and the group will then draw up subsequent work plan.

Dr Susie Shapiro,
Chair, Co-Morbidities Working Party
October 2021