

Co-Morbidities Working Party

Membership

Chair	Dr Susie Shapiro, Oxford
UKHCDO representatives:	Dr Gary Benson, Belfast Dr Gillian Evans, Canterbury Prof Charles Hay, Manchester Prof Mike Makris, EUHASS Dr Rhona Maclean, Sheffield Dr Sarah Mangles, Basingstoke
Haemophilia Nurses Association Representative:	Cathy Harrison, Sheffield

Remit

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 (New remit - Jan 2020)

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.

Meetings

Since January 2020 we have held scheduled 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); and to agree and progress further Work Plan.

Activities

Adverse events of special interest. 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 requires minimum of 3 members of the group to be present. All relevant historic reported events on Emicizumab have been reviewed and the group is up-to-date with newly reported events (any product). The consensus decision of reported events is included in this annual report. In the future the plan will be that any serious adverse events will be fed back rapidly to UKHCDO membership, and otherwise a regular report will be sent round, frequency dependent on number of events reported.

Cardiovascular events and bleeding disorders. The group agreed to perform and write-up a systematic review on cardiovascular events in patients with bleeding disorders (prevalence and treatment) in order to highlight areas for future work. This is currently underway.

Dr Susie Shapiro,
Chair, Co-Morbidities Working Party
October 2020

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