

UK Haemophilia Data Managers Forum Group

The UK Haemophilia Data Managers Forum (HDMF) has met twice since the last UKHCDO annual report. The group were invited to join the UKHCDO for a two-day meeting in Manchester in November 2011 and also held a meeting in early September 2011.

November 2010

The group was pleased to be invited to join the UKHCDO members for presentations on the Thursday and also to join the UKHCDO members for the reports from the working parties on the Friday.

As usual, prior to the HDMF business meeting, there was an update from MDSAS on NHD developments and projects, including:

- New HCIS Electronic Patient Record (EPR)
- Haemtrack
- Genetics module for the NHD
- Genetics testing Network Laboratories
- RFID – Radio Frequency Identification and Regulatory and Industry Reporting

Discussions at the business meeting included:

- Hepatitis C Look-back Exercise
- Home Delivery
- Presentation by Pfizer - Pfizer in Haemophilia

September 2011

The two-day meeting in September in Coventry was very popular and included two presentations by Novo Nordisk - A Brief Overview of Haemophilia and Health Economic Considerations in Haemophilia.

The business meeting also included an interesting presentation by Dr Charles Hay, Chairman of UKHCDO, who spoke to the group about the drivers of data collection, including;

- National Contracting (CMU)
- Benchmarking of Haemophilia Centres
- Disease monitoring, including vCJD monitoring and Hepatitis C look-back
- Pharmacovigilance, Thrombogenicity monitoring and Inhibitor surveillance
- Research, Epidemiology of haemophilia and its complications

Other agenda items included the use of NHS.net email accounts, for secure transmission of data from one NHS organisation to another, and a very interesting analysis of the home delivery questionnaire carried out by the Nancy Brodie.

Jan Bevan from the Commercial Medicines Unit spoke to the group about “CMU’s role in the contracting process”. She gave a very informative insight into the framework agreement process.

Change of Executive Officers

The UK Haemophilia Data Managers Forum group has now been meeting since May 2005. Nancy Brodie and Lynne Dewhurst’s three year term of office as Chair and Secretary respectively expired in May 2008. Both were eligible for a second period of office and at the meeting in May 2008 both were re-elected.

The offices of Chair and Secretary came up for re-election this year and, after 6 years as office bearers for the group, neither Nancy nor Lynne wished to continue in an official capacity in the group.

At the meeting in September, the group elected Heather Williams as the new Chair and Miriam Elliot as the new Secretary.

Nancy and Lynne would like to thank the UKHCDO Executive, Advisory Committee and Data Management Working Party, in particular Drs. Hay and Dolan, for all their support in getting this group established and for their continued support during their two terms of office. They would also like to wish Heather Williams and Miriam Elliot best wishes for the future in their new roles.

Lynne Dewhurst, Outgoing Secretary
UK Haemophilia Data Managers Forum
September 2011