

UK Haemophilia Data Managers' Forum

Nancy Brodie

Chair

Lynne Dewhurst

Secretary

Both office bearers continue for next 3-year period.

The UK Haemophilia Data Managers' Forum Group supports and encourages those who are responsible for the collation and analysis of Haemophilia data within the United Kingdom. At present this group has a membership of 164. Haemophilia data managers are now considered a key part of the team as the continuous need for accurate data becomes increasingly important in this low volume, high cost area of the NHS.

Over the past year the Group has held two meetings, one in November 2016 and the other more recent in May 2017. 25 members attended both meetings.

Following the 2016 meeting held in Manchester, a short survey was carried out to establish some of the problems members had with facilitating attendance at these meetings. The main issue, reported by most members, was the travel distance. It was with this in mind that the following meeting was held in Birmingham in May 2017. Another issue identified was staffing pressures causing members to have to miss the meetings. It is hoped that Centre Directors will highlight the importance of data managers being allowed to attend these meetings with management colleagues within hospital trusts.

The agenda at both meetings included presentations on topics very current in haemophilia and relevant to the Group with members being encouraged to present interesting topics to their peers.

A presentation on Enhanced Half Life (EHL) products (Dr Pratima Chowdary) gave a good insight into the possible benefits to some patients these products may have and explained why patients had to go through an individual testing process before they could be considered eligible for switching to these new products and could not just be transferred over in large groups.

In May 2017 Commercial Medicines Unit (CMU) (Alison Greenwood and Wendy Roach) brought the Group up to date with who CMU are, the tender process and the process of including new EHL products in this next round of contracting. This also highlighted and was a reminder of the legalities by which we are all bound during the contracting process.

Will Horsley, Lead Commissioner for Specialised Blood Disorders, NHS England also gave a presentation entitled "Haemophilia Dashboard" at this meeting, which demonstrated the importance of reporting accurate data and how these key performance indicators are actually used.

Thank you to all who took time from their busy schedules to give these informative presentations.

The mentoring programme for new haemophilia data managers continues where and when necessary with the booklets published in 2016 proving very useful for reference purposes.

SOBI and CSL supported the November and May meetings respectively, this funding is invaluable to facilitating these meetings and for their sponsorship we extend our thanks.

On behalf of the Group, I would also extend our thanks to both the UKHCDO Executive/Advisory Committees and Data Management Working Party for ongoing support and encouragement.

Nancy Brodie
Chair, UK Haemophilia Data Managers' Forum Group
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