

Haemophilia Alliance

Membership

Co-chair from UKHCDO – Dr Jonathan Wilde, Director of the West Midlands Adult CCHC, University Hospital Birmingham.

Co-chair from Haemophilia Society – Ms Liz Rizutto

UKHCDO representatives – Dr Pratima Chowdary, Royal Free Hospital, London, Dr Bella Madan, Guy's and St Thomas' Hospital, London & Dr Steve Austen, St Georges Hospital, London.

UK Haemophilia Society – Mr Chris James, Mr Matt Gregory, Mr Dan Farthing, Mr Steve Wratten & Mr Mark Ward.

The Haemophilia Nurses Association – CNS Colette McAfee, Belfast CCHC, CNS Anica Phillott, St Thomas' CCHC, CNS June Ward, Dundee HC & CNS Angela Westoby, Leeds CCHC.

The Haemophilia Chartered Physiotherapists Association – Mr Steven Clacey.

The Haemophilia Social Workers Group – Mr Mark Simmons, West Midlands Adult CCHC, University Hospital Birmingham.

The Clinical Scientists Group for Haemophilia – Dr Bimal Theophilus, West Midlands Children's CCHC, Birmingham Children's Hospital.

The Biomedical Laboratory Scientists – Ms Jane Needham, North Hampshire Hospital, Basingstoke.

The membership of the Alliance during 2011/2012 is listed above. Liz Rizutto has replaced Roddy Morrison as the UK Haemophilia Society co-chair and Anica Philpott has replaced Christine Harrington.

The future role of the Alliance is uncertain following the reorganisation of NHS commissioning and the establishment of the National Clinical Advisory Group for Haemophilia. However it has been decided that the direct interaction between the Alliance membership and the UK DOH blood policies agencies is still very valuable and so the group will continue to exist for the foreseeable future.

During the year meetings of the Alliance /DOH have taken place on 14th November 2011 and 25th May 2012 at Wellington House in London. Representatives from the DOH blood policy units of England (Mrs Rowena Jecock), Scotland (Mr Robert Girvan) and Wales (Ms Jenny Thorne) have been in attendance. Miss Jan Bevan of the NHS Commercial Medicines Unit and Mr Keith Chidwick of the European Medicines Agency attended the May meeting.

Issues covered during the last year have included the new national specialised commissioning arrangements, the performance of the national concentrate purchasing

contract, the hepatitis C look back exercise, the new arrangements for the UKHCDO triennial audit of CCCs and the new European Medicines Agency guidelines on plasma derived medicinal products. At the May meeting there was a presentation from Andrew March covering the issues encountered in hospital by patients in the variant CJD at risk group and a request to provide improved information concerning vCJD to patients and health care staff.

The Alliance Industry Forum has had one meeting this year. This was held on 26th March 2012. As usual a wide representation from the commercial companies marketing factor products within the UK attended and were updated on the major issues of the moment concerning haemophilia care.

Dr Jonathan T. Wilde
Haemophilia Alliance
August 2012