

# 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** – Mr Roddy Morrison

**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 Chris Harrington, Royal Free Hospital CCHC, London, CNS Angela Westoby, Leeds CCHC, CNS June Ward, Dundee HC

**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 2010/2011 is listed above. Drs Chowdary and Austen representing UKHCDO and Mr Wratten and Mr Ward representing the Haemophilia Society have joined the group.

## Meetings

During the year there have been two meetings held jointly with the DOH at Wellington House in London on 19<sup>th</sup> November 2010 and 13<sup>th</sup> May 2011. Representatives from the blood policy units of England and Scotland were in attendance with Welsh representatives participating by conference link.

## Discussion Topics

A wide range of topics have been covered at the meetings. Major topics have included issues surrounding the revised Skipton Fund payment scheme, updates on the progress of the new arrangements for commissioning of specialist services in England and the progress of the Penrose Inquiry. At the November meeting there was a presentation on personal health budgets by DOH representatives and a discussion about suitability of implementation of these for haemophilia patients with long term needs.

The Alliance is in the process of updating the National Service Specification for Haemophilia and hope to incorporate into this the new model of haemophilia care arrangements arising out of the rewrite of HSG (93) 30 which is being undertaken at the time of writing.

The Alliance Industry Forum continues to function. During the last year meetings were held on 1<sup>st</sup> October 2010 and 25<sup>th</sup> March 2011. Mrs Jan Bevan head of factor procurement at the NHS Commercial Medicines Unit has joined the group. The main agenda items have been issues regarding the performance of the national clotting factor contract, the proposed re-designation of UK Haemophilia services, the reorganisation of specialist commissioning services in England and the impact this will have on contracting haemophilia care.

Dr J T Wilde  
June 2011