

# Rare Disorders Working Party

## Membership

Andrew Mumford                      Chairman  
Sam Ackroyd  
Raza Alikhan  
Louise Bowles  
Pratima Chowdary  
John Grainger  
Jason Mainwaring  
Mary Mathias  
Niamh O'Connell

## Meetings

The group met face to face on 14<sup>th</sup> November 2013 (Mumford, Mathias, Mainwaring, Alikhan, Bowles, Ackroyd, O'Connell)

In addition there were 6 teleconferences in 2103 in two sub-groups

## Remit

The main activity of the working party has been completion of the 2014 Rare Coagulation Disorders Guideline. This has now progressed through consultation, sounding, submission, peer-review and editorial processing at the British Journal of Haematology. The guideline is now available as an Epub ahead of print.

## Activities

The working party has collaborated with the Paediatric Working Party to design a UK survey of intracranial haemorrhage in haemophilia and rare coagulation and platelet disorders and has contributed to a UKHCDO consultation on adoption of recombinant FXIII concentrate for prophylaxis in FXIII deficiency. The working party has facilitated launch of the EU Prospective registry of FXIII and fibrinogen deficiency at UK centres within the EUPHANET consortium framework. On-going projects include a retrospective survey of UK prescribing practice for rare coagulation disorders (with Data Management Working Party).

## Publications

Guideline for the diagnosis and management of the rare coagulation disorders: A United Kingdom Haemophilia Centre Doctors' Organization guideline on behalf of the British Committee for Standards in Haematology.

Mumford AD<sup>1</sup>, Ackroyd S, Alikhan R, Bowles L, Chowdary P, Grainger J, Mainwaring J, Mathias M, O'Connell N; the BCSH Committee

Br J Haematol. 2014 Aug 6. doi: 10.1111/bjh.13058. [Epub ahead of print]

Dr Andrew Mumford  
Chairman, Rare Disorders Working Party  
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