

# Rare Disorders Working Party

## Membership

Dr Andrew Mumford (Chair)  
Dr Sam Ackroyd  
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Dr Louise Bowles  
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Dr John Grainger  
Dr Jason Mainwaring  
Dr Mary Mathias  
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The rare disorders WP has a track record of publication of highly cited management guidelines [1,2] but has not been active since 2009. A newly convened group was reformed in August 2012 and comprises UK Haemophilia clinicians with personal expertise in diagnosis and management of rare disorders. The main remit of the WP is to update the 2004 'rare coagulation disorders' guideline which is now obsolete. The revised guideline will have greater focus by omitting ehlers-danlos syndrome but will include the fibrinolysis pathway disorders PAI-1 deficiency and antiplasmin deficiency. Descriptions of individual disorders will be in standardised sub-headings to improve clarity and brevity. Draft sections are now with the members of the WP and will be assembled into a first draft manuscript in Q1 2013. The WP has the secondary task of collaboration with the data management WP to revise the UKHCDO database diagnostic classification of the rare coagulation and platelet disorders.

1. Bolton-Maggs PHB, Chalmers EA, Collins PL, Harrison P, Kitchen S, Liesner RJ, Minford A, Mumford AD, Parapia LA, Perry DJ, Watson SP, Wilde JT, Williams MD.

A review of inherited platelet disorders with guidelines for their management on behalf of the UKHDCO. *British Journal of Haematology* 2006; 135: 603-633.

2. Bolton-Maggs PHB, Perry DJ, Chalmers EA, Parapia LA, Wilde JT, Williams MD, Collins PL, Kitchen S, Dolan G, Mumford AD.

The rare coagulation disorders- review with guidelines for management. *Haemophilia* 2004; 10: 593-628.

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