Rare Disorders Working Party

Membership

Dr Andrew Mumford (Chair)
Dr Sam Ackroyd
Dr Raza Alikhan
Dr Louise Bowles
Dr Pratima Chowdary
Dr John Grainger
Dr Jason Mainwaring
Dr Mary Mathias
Dr Niamh O’Connell

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.


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

Dr Andrew Mumford
Chair, Rare Disorders Working Party
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