8. Von Willebrand Disease Working Party

Membership

Prof John Pasi	Chairman
Dr Tony Cumming	
Dr Anne Goodeve	
Prof Frank Hill	
Dr Mike Laffan	
Dr Will Lester	
Dr Ian Peake	

Remit

The VWD Working Party has been re-established with a draft remit as below

- Review of guideline documents
- Over view of the type 1 molecular study
- Review of VWD notifications and data on national database to explore the need and feasibility of Data Cleaning
- Developing closer links with obstetricians / gynaecologists
- Establish the place of platelet VWF measurements in the diagnosis of VWD
- Consider areas of controversy in DDAVP use (type 2B, children etc)

The main activities of the Working Party during the year are summarised below:

The VWD Working Party has recently been reformed and met in early September to consider and revise the new draft remit and timescales. The national molecular study has continued, with data presented at scientific meetings and submitted for publication.

Publications

Cumming A, Grundy P, Keeney S, Lester W, Enayat S, Guilliatt A, Bowen D, Pasi J, Keeling D, Hill F, Bolton-Maggs P, Hay C, Collins P on behalf of the UK Haemophilia Centre Doctors' Organisation
An investigation of the von Willebrand factor genotype in UK patients diagnosed to have type 1 von Willebrand disease. Thrombosis and Haemostasis, 2006: *in press*

Prof KJ Pasi
September 2006