

von Willebrand Disease Working Party

The VWD working party has met formally once in the last year.

Most of the work has been conducted in a series of teleconferences with MDSAS/NHD and email circulars.

Membership		and	Attendance	
M Laffan (Chair)	1/1		A Will	1/1
D Keeling	1/1		C Tait	1/1
J O'Donnell	0/1		A Goodeve	1/1
W Lester	1/1		C Millar	1/1

Activities

Publication of UKHCDO guidelines

The 2014 guidelines were published shortly after last year's annual report. (The diagnosis and management of von Willebrand disease: a United Kingdom Haemophilia Centre Doctors Organization guideline approved by the British Committee for Standards in Haematology: BJH 167: 453-465)

Database and VWD registration

The entire set of data entries for VWD on the NHD have been reviewed. As expected they show an irregular and inconsistent pattern of registrations, many of which are clearly incorrect.

In a series of teleconferences the registration process for VWD has been thoroughly reviewed and revised. A new registration page has been drawn up with a complete revision of the data fields required, removal of duplication and obsolete measurements. A plan for migration of pre-existing registrations has also been drawn up. Following completion by MDSAS this is now ready for implementation.

Data correlation and the NHS workload

Permission has been obtained from the Data Management Working Party to use the NHD to correlate VWD diagnosis with the NHS data warehouse on hospital admissions. It is hoped that this will allow us to assess or estimate the additional burden of VWD (or related bleeding disorders) on the NHS. Clarification of data linking permission or requirement of article 251 permission to do this is being reviewed.

Professor Mike Laffan
Chairman, von Willebrand Disease Working Party
September 2015

