

Von Willebrand Working Party

Membership

Dr Carolyn Millar

Chair

Cathy Farrelly

Vince Jenkins

Mike Laffan

Will Lester

Shapiro Susie

Thynn Thynn Yee

Henry Watson has recently retired and has stepped down from the Working Party.

Meetings

The VWD working party has not met formally since the last AGM.

Summary of activities

The WP is working on the following projects:

1. Revision and update of BCSH/UKHCDO 2014 guidelines.

It has been agreed with the BSH taskforce that the guideline will be divided into two separate documents: a clinical guideline and a laboratory testing guideline.

The UKHCDO laboratory working party has together with the BSH taskforce set up a joint writing group chaired by Sean Platton for the laboratory guideline. In parallel, the VWD working party will be revising and updating the clinical guideline, with consideration of the 2021 ASH/ISTH/NHF/WFH guidelines on the Diagnosis and on the Management of VWD. One particular challenge we face is our response to the recent change in position adopted by ASH/ISTH who have abolished the distinction between 'low VWF' and type 1 VWD. We had introduced the 'low VWF' category into the 2014 guideline in accordance with expert scientific opinion and contemporaneous international consensus. In brief, the 'low VWF' category places emphasis on risk factor rather than disease, directs further investigation where indicated and facilitates appropriate counselling and relative testing. Detailed review of scientific evidence and consideration of how the current ASH/ISTH position was reached will be required to inform the UKHCDO position and guidance going forward.

2. The new registration process and forms for VWD remain under review. For example, we should now be looking to incorporate the addition of VWD Type 1C (accelerated clearance such as Vicenza) to registration following the recent recognition by ISTH of 1C as a subtype. Clarification of definition is pending. The implementation of rules to avoid nonsense entries remains.
3. Lists of patients whose entries require review by the registering centre with a view to updating, reclassifying or removing have been compiled by NHD. Discussion has previously taken place with NHD about compiling these lists and how to revise the registrations. Some centres have large numbers and to avoid sending details all at once, a stepwise plan for NHD to send a limited number to centres every 2 months with a request for them to review the cases and update or

delete them. This work needs to be followed up with relevant personnel at NHD (previously Tom).

Dr Carolyn Millar,
Chair, Von Willebrand Working Party
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