

Von Willebrand Working Party

Membership

Prof Mike Laffan

Chair

Anne Goodeve

Keith Gomez

Henry Watson

Carolyn Millar

Shapiro Susie

Thynn Thynn Yee

Vince Jenkins

Will Lester

The VWD working party was reformed in 2017 and the above membership agreed.

Since the last AGM the WP has worked on the following projects:

1. The registration process for VWD. The registration pages for VWD on the national database have been fully rewritten. This updates to include new measurements, new criteria and removes some historical outdated tests and duplications. It incorporates a link to genetic data. This is now complete although the implementation of rules to avoid nonsense entries remains.
2. The existing entries on the VWD database. Review of the entries indicates that many are erroneous and do not fulfil the criteria for the category in which they are entered. We have discussed plans to correct this with the NHD. This will be a considerable amount of work but necessary for meaningful data and research in the future. Centres will be contacted in a rolling fashion about removing and reclassifying patients.
3. The VWD WP has also been involved in drawing up the policy document and public consultation process for recombinant VWF.

The American Society of Hematology (ASH) guidelines on diagnosis and management of VWD are still in progress and are expected in 2020. These will be reviewed when published and the need for new UK guidelines considered.

Prof Mike Laffan,
Chair, Von Willebrand Working Party
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