

von Willebrands Disease Working Party

Members

M Laffan (Chair)
D Keeling
J O'Donnell
W Lester
J Pasi
C Millar
A Will
C Tait
A Goodeve
(Possible data management representative)

The first meeting of this reconvened WP will be on the 8th November 2012

Proposed topics will include

1. Review diagnostic and treatment guidelines of 2004
 - a. Extension of AVWS and management of inhibitors components
2. Review National database records of VWD: audit use of this diagnostic category
3. Review methods, fields and criteria for registering VWD
 - a. How severity should be recorded – with reference to the limits of the assays available.
 - b. Role of genetic data: for all or for subgroups
 - c. Role of collagen binding assays (which)?
 - d. Any need to consider age effects? (or evidence from database?)
 - e. Combination with data from Irish database
4. Other topics will be invited and discussed.

Prof Mike Laffan
Chair, von Willebrands Disease Working Party
June 2012