

## **MASAC RECOMMENDATION REGARDING THE NEED FOR UPDATED GUIDELINES FOR DIAGNOSIS AND MANAGEMENT OF VON WILLEBRAND DISEASE**

*This document was approved by the Medical and Scientific Advisory Council (MASAC) on September 20, 2014, and adopted by the NHF Board of Directors on September 21, 2014.*

Von Willebrand disease (VWD) is a common, mild to severe bleeding disorder for which the diagnosis and treatment remain less than optimal. There are hereditary and acquired causes of von Willebrand Factor (VWF) deficiency, including abnormalities in both concentration and function. Since VWF is an integral part of the FVIII/VWF complex, VWD symptoms, in part, relate to VWF's role in maintenance of FVIII activity and in the localization and physiological activation of clotting. This disorder is therefore within the purview of MASAC and the National Hemophilia Foundation.

In 2007, NHLBI convened an advisory committee to develop guidelines for the diagnosis, evaluation, and management of VWD; they were finalized in 2008. (1) These guidelines were endorsed by multiple organizations, including the National Guidelines Clearinghouse (NGC), MASAC and ASH. After 5 years, these guidelines have now been withdrawn from the NGC, and NHLBI has decided not to update them.

MASAC recognizes the critical need to maintain active, relevant guidelines concerning the diagnosis, evaluation, and management of VWF and to support the clinical needs of individuals with VWD and of individuals who are being evaluated for this disorder.

MASAC therefore recommends that NHF convene a workshop to ascertain the needs of the patients, physicians, and scientists in order to update the guidelines and to establish the priorities for further development and active maintenance of these guidelines as needed.

### Reference

1. Von Willebrand Disease (VWD): evidence-based diagnosis and management guidelines, the National Heart, Lung, and Blood Institute (NHLBI) Expert Panel report (USA). *Haemophilia* 2008; 14: 171-232.

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