



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

MASAC Document #232

**MASAC RECOMMENDATIONS ON THE CARE AND TREATMENT OF
INDIVIDUALS WITH VON WILLEBRAND DISEASE**

The document was approved by the Medical and Scientific Advisory Council (MASAC) on April 18-19, 2015, and adopted by the NHF Board of Directors on June 4, 2015.

A von Willebrand disease (VWD) Summit organized by NHF focused on gaps in the care of individuals with VWD. A summary of the discussion highlighted the following issues: 1) Patients with VWD feel stigmatized and marginalized in terms of access to care. 2) Difficulties in making the diagnosis and physicians' lack of agreement about elements of the diagnosis contribute to patients' feelings of uncertainty. 3) There is currently no national organization that promotes VWD care.

Based on these findings from the vWD Summit, MASAC recommends:

1. NHF should be the primary organization to promote vWD care and to provide leadership and advocacy for persons with vWD.
2. NHLBI vWD Guidelines, which are now 10 years old, should be reviewed and updated.
3. Education of vWD patients, families, and healthcare providers should be increased at both the national and local level.
4. Development of new treatments for vWD should be continued, with increased funding for both basic and translational research.
5. Standardization of diagnostic assays and access to those assays are needed nationwide.

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