



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

VWD Toolkit for Women, Girls, and Individuals with the Potential to Menstruate





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Dear Community Member,

The National Hemophilia Foundation (NHF) wants to welcome you to the bleeding disorder community. We know that receiving a diagnosis of von Willebrand disease (VWD) can bring up mixed emotions and more questions. Therefore, we created this VWD Toolkit for newly diagnosed individuals and families, to help address some of those questions, concerns, and needs. As you embark on this journey, we hope the toolkit helps you to begin putting pieces of the VWD puzzle together.

In the toolkit you will find several resources, they are all listed on the following page under "Key of Resources". These tools can be helpful in your VWD journey; however, you may not need to use all of them. Be sure to read through the entire toolkit and use what can be applied to your individual situation.

While the VWD Toolkit has a lot of great information, you may still have questions. We encourage you to reach out to your hemophilia treatment center or healthcare provider with any questions or concerns about your diagnosis and treatment. We also suggest visiting NHF's educational website <https://stepsforliving.hemophilia.org/> to learn more about living with a bleeding disorder through all stages of life. Or you can contact HANDI, NHF's information resource center at handi@hemophilia.org. NHF also thanks all those involved in creating this toolkit, our dedicated working group that developed this kit, and our sponsors.

In Good Health,

Leonard A. Valentino, M.D.
President and Chief Executive Officer



Click the underlined text in the lefthand column to access resources

VWD Specific NHF Resources	Description
<u>VWD Brochure</u>	Learn more about the basics of VWD.
<u>VWD Piecing Together the VWD Puzzle</u>	Learn more about living with VWD.
<u>VWD Youth Activity Book</u>	Activity book for children with VWD.
<u>Let's Talk Puberty</u>	This companion piece to Time to Talk Puberty discusses tips for parents and caregivers for discussing puberty with young person in their life including conversation pointers, and questions to ask.
<u>Time to Talk Puberty A Guide for Girls with Bleeding Disorders</u>	This companion piece to Time to Talk Puberty discusses tips for parents and caregivers for discussing puberty with young person in their life including conversation pointers, and questions to ask.
<u>VWD Guidelines Diagnosis Snapshots – English Version</u>	The snapshots provide a high-level summary of diagnosing of VWD.
<u>VWD Guidelines Management Snapshots – English Version</u>	The snapshots provide a high-level summary of the management of VWD.
<u>VWD Diagnosis Guidelines (NHF summary)</u>	Summary of the guidelines on the diagnosis of von Willebrand Disease (VWD).
<u>VWD Management Guidelines (NHF summary)</u>	Summary of the guidelines on the management of von Willebrand Disease (VWD).
<u>Nosebleeds</u>	Created in collaboration with NHF's Nursing Working Group and nurses from Canada, this publication describes the unique issues a person with a bleeding disorder faces with a nosebleed. Causes of nosebleeds, basic treatment, when to consult the bleeding disorder treatment center and prevention issues are discussed.



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Better You Know (BYK) Resources	Description
<u>BYK What Women and Girls Should Know About Getting Tested for Bleeding Symptoms</u>	This brochure is a guide to lab tests, screening tools, and health exams. A comprehensive glossary of terminology is included.
<u>BYK Lab Test Log</u>	This form tracks what tests were ordered by a healthcare provider, when tests were given, and the test results.
<u>BYK Menstrual Chart and Scoring System</u>	This form tracks the menstrual flow according to saturation with tampons or pads.
<u>BYK Teen Girls Brochure: It's Your Health.</u>	This guide provides information to teens about periods, bleeding disorders, and how to prepare for a visit with your healthcare provider.
<u>BYK Doctor Visit Preparation</u>	A list of questions to help guide conversation when talking with a healthcare provider to get the most out of each provider visit.
<u>BYK Healthcare Diary</u>	Diary list of symptoms and health history questions to fill out prior (month or two) to a provider visit.



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Miscellaneous NHF Resources	Description
<p><u>Guidelines for Emergency Department Management of Hemophilia and Other Bleeding Disorders</u></p>	<p>A trip to the Emergency Department (ED) can be scary and stressful. MASAC For You – Guidelines for Emergency Department Management of Hemophilia and Other Bleeding Disorders, provides steps to help you prepare for an emergency department visit and includes important information to help navigate productive conversations with emergency department staff.</p>
<p><u>Playing it Safe: Bleeding Disorders, Sports, and Exercise</u></p>	<p>This comprehensive educational booklet describes the importance of physical activity for joint health and overall wellness in people living with bleeding disorders. It provides an overview of various sports and activities for all stages of life and addresses how to participate in physical activity safely.</p>
<p><u>Mental Health Hotlines</u></p>	<p>This list is for individuals and families affected by bleeding disorders who are in crisis. Individuals experiencing a life-threatening situation or having thoughts of self-harm or harming others should seek immediate assistance by calling 9-1-1 or going to the nearest emergency department.</p>