NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

Leonard A. Valentino
President and Chief Executive Officer

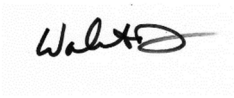
Dear Community Member,

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,



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Key of Resources

VWD Specific NHF Resources

- VWD Brochure
- VWD Piecing Together the VWD Puzzle
- VWD Youth Activity Book
- Let's Talk Puberty
- Time to Talk Puberty A Guide for Girls with Bleeding Disorders
- VWD Guidelines Diagnosis Snapshots – English Version
- VWD Guidelines Management Snapshots – English Version
- VWD Diagnosis Guidelines (NHF summary)
- VWD Management Guidelines (NHF summary)
- Nosebleeds

Better You Know (BYK) Resources

- BYK What Women and Girls Should Know About Getting Tested for Bleeding Symptoms
- BYK Lab Test Log
- BYK Menstrual Chart and Scoring System
- BYK Teen Girls Brochure
- BYK Doctor Visit Preparation
- BYK Healthcare Diary

Misc. Resources

- For Girls with Bleeding Disorders: What to Expect During Your First Gynecological Exam – English Version
- Guidelines for Emergency Department Management of Hemophilia and Other Bleeding Disorders