

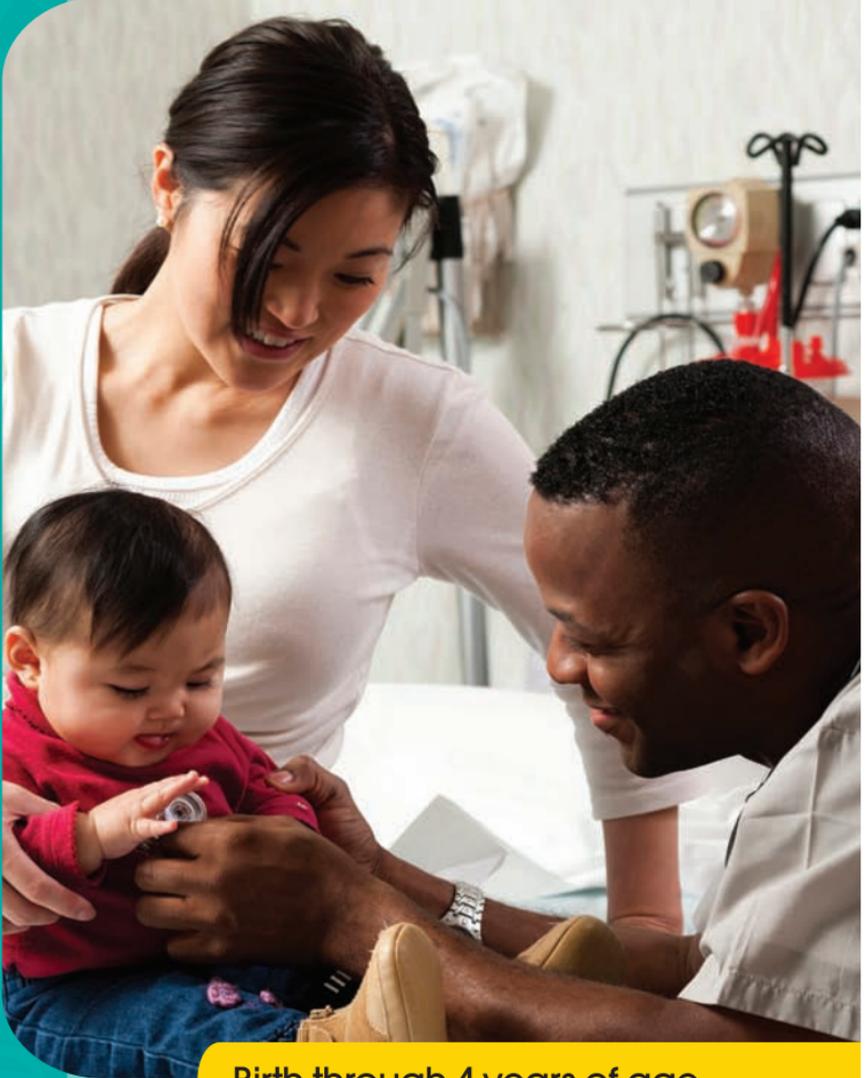
10 Things Everyone Should Know About Bleeding Disorders

- 1** People with bleeding disorders do not bleed any more than those without bleeding disorders; they just bleed longer because their bodies are missing the necessary elements to form a clot.
A simple cut will not cause a person with a bleeding disorder to bleed to death.
- 2** People with bleeding disorders are just like everyone else. Aside from a few special medical needs and precautions, they can fully participate in a wide range of activities.
- 3** People with bleeding disorders can manage most of their care from home under the guidance of health professionals.
- 4** People with bleeding disorders should get a comprehensive check up from a hemophilia treatment center (HTC) once a year.
A landmark Centers for Disease Control and Prevention (CDC) study found that people who received care in hemophilia treatment centers (HTCs) lived longer and were less likely to be hospitalized for bleeding complications than non-HTC users.
- 5** Prophylaxis is the best therapy for individuals with severe hemophilia A or B (factor VIII [8] or factor IX [9] deficiencies). Break-through bleeds should be treated early and adequately!
- 6** People with bleeding disorders should exercise and maintain a healthy body weight.
Having strong muscles helps stabilize joints and can reduce the risk of injury and bleeds.
- 7** Knowing and understanding the person's diagnosis and treatment regime is important.
Knowing the diagnosis and treatment regime is critical in order to clearly communicate needs of those of your loved one in an emergency.
- 8** There is an education and support network through the local HTC or local bleeding disorder organization.
There are many ways to connect with others living with bleeding disorders or caring for those with bleeding disorders. Please contact HANDI (1-800-42-HANDI; 1-800-424-2634) or handi@hemophilia.org to find out how you can become connected.
- 9** Women can have bleeding disorders, too!
Women with bleeding disorders take an average of 16 years between reporting symptoms to a clinician and subsequent accurate diagnosis. Learn the signs and symptoms to help reduce this lag time.
- 10** The person with a bleeding disorder is the most important part of the treatment team. People with bleeding disorders should take an active role in managing their care.
Work with your medical team to ensure that you understand all aspects of your care so that you continue to live a long and healthy life.

Birth-4

Guidelines for **Growing:**

An action plan for parents
of children with bleeding disorders



Birth through 4 years of age



**Centers for Disease
Control and Prevention**
National Center on
Birth Defects and
Developmental Disabilities



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding and clotting disorders

Birth through 4 years of age

Young children with bleeding disorders face a number of difficult and ongoing medical challenges as they mature and learn to manage their bleeding disorders. As a parent of a child with a bleeding disorder, it is important for you to be aware of what you can do to help your child as he or she transitions through his or her life stages. This is the first age-specific brochure in the *Guidelines for Growing* series, adapted from the National Hemophilia Foundation's (NHF) Medical and Scientific Advisory Council* (MASAC) Transition Guidelines. Each brochure focuses on important milestones of your child's development as they relate to his or her bleeding disorder. This resource is designed to be used in conjunction with your hemophilia treatment center (HTC) provider team to guide you as you help your child grow and develop.

1. Social Support and Resources

- ✓ Attend local and national events for people within the bleeding disorders community throughout the year. Attending these events with your child will help you connect with others and get the support you need. Ask your HTC team or local bleeding disorders organization about programs, group sessions, and social activities with other parents of children with bleeding disorders. For a list of NHF chapters and other local bleeding disorders organizations, as well as a list of national events and their locations, visit the NHF Web site at www.hemophilia.org.
- ✓ Request resources from your HTC team or NHF chapter. Visit NHF's Steps for Living

Web site at www.stepsforliving.hemophilia.org or contact HANDI, NHF's information resource center (1.800.42.HANDI/1.800.424.2634) to speak to an information specialist about publications and brochures. Also visit www.hemaware.org to find NHF's bleeding disorders magazine available online.

- ✓ Search for your local HTC on the Centers for Disease Control and Prevention (CDC) Web site (www.cdc.gov/ncbddd/hemophilia/HTC.html). Search for your local NHF chapter on the NHF Web site (www.hemophilia.org).

2. Health and Lifestyle

- ✓ Implement safety measures in your home and vehicle(s). Ask members of your HTC team or local bleeding disorders organization about child-proofing your home, proper car seat use, emergency preparedness checklists and other safety measures.
- ✓ Discuss the use of safety gear (padded helmets and knee and elbow pads) with your HTC team. Buy or borrow the recommended items.



- ✓ Discuss infant and toddler oral health with your HTC team. Ask for a list of dentists familiar with treating people with bleeding disorders.
- ✓ Be positive. Stress your child's abilities, not disabilities, both with your child and with others with whom your child will interact.
- ✓ Protect your child with medical alert identification tags or emblems. That way, your child's bleeding disorder and emergency contact information can be identified in the event that the child is not able to speak for himself or herself, or is not old enough to explain. Your HTC team, NHF chapter members and HANDI can provide you with information about these programs.

3. Educational Planning

- ✓ Explore available day care, child care and preschool options in your community. Interview providers carefully using "The Child With A Bleeding Disorder: Guidelines For Finding Childcare", an NHF brochure available from your HTC, NHF chapter or HANDI.

4. Self-Advocacy and Self-Esteem

Express Medical and Physical Needs

- ✓ Explain the need for clotting factor infusions positively to your child and others. Avoid making your child feel that clotting factor infusions are a punishment for his or her behavior.
- ✓ Teach your child to recognize and report pain or symptoms of a bleed as soon as possible.

- ✓ Ask your HTC, NHF chapter or HANDI for age-appropriate books and other materials for your child about living with a bleeding disorder.

Understand Rights and Responsibilities for Your Child's Health Care

- ✓ Learn what insurance options are available for your family. Some states have insurance programs for eligible children with chronic medical needs. If you already have health insurance, make sure you understand what services and treatments are covered and whether there are limits on coverage. Contact your local NHF chapter and HANDI to request educational materials on health coverage.
- ✓ Learn about patient rights and responsibilities. Ask for the NHF patient bill of rights, available through HANDI.
- ✓ Learn about confidentiality laws related to health care, such as the Health Insurance Portability and Accountability Act (HIPAA). Research HIPAA information on the U.S. Department of Health and Human Services Web site (www.hhs.gov). Consider keeping your own set of your child's medical records with clinic summaries and laboratory and imaging reports.

5. Independent Health Care Behaviors

Participate in Treatments and Decision Making

- ✓ Discuss signs and symptoms of bleeding with your HTC team. Learn to assess your child for bleeding problems and determine what treatment or medical attention is required.
- ✓ Learn about treatment products so that you can make informed decisions together with your HTC team.

- ✓ Begin to learn the steps of treating bleeds (i.e., mixing factor).
- ✓ Learn about options for administering factor into a vein. Discuss these with your HTC team.
- ✓ Speak with your HTC team about treatment options, such as on-demand therapy (treating with clotting factor at the time of a bleeding episode), prophylaxis (regularly scheduled clotting factor treatment), and activity-related prophylaxis (treating before an activity to prevent bleeding). Become an informed consumer.
- ✓ Discuss with your HTC team the universal precautions recommended for all people handling clotting factor infusion equipment. Gloves should be worn by people who prepare or infuse products, and during disposal of clotting factor infusion equipment and waste. A needle that has broken the skin should not be reused; used needles should never be recapped. Used needles should be placed in a sharps container in a location inaccessible to young children.

Keep Records and Communicate With Health Care Providers

- ✓ Keep a list of important telephone numbers for emergencies. Include contact information for your pediatrician, HTC, factor provider, home health nurse and local emergency room. Make sure it is in a place that is easy to access, and that your child and other family members know where to find it.
- ✓ Obtain and maintain copies of letters from your HTC specifying your child's diagnosis and treatment protocol.

- ✓ Always call your HTC before you head to an emergency room so they can notify the medical personnel of your arrival. Do not be intimidated by emergency room personnel. Insist that they contact your HTC if you question their treatment plan.
- ✓ Learn about options, either electronic or paper, for keeping your child's treatment log.
- ✓ Be sure to call your HTC if you have any questions, especially during the first few years. Write down any questions so that you can ask your HTC team during your child's next visit.

Begin Planning for Your Child's Active Life

- ✓ Learn about expected developmental stages for infants and toddlers. Plan ahead for safety and other adaptations or protective steps that might be necessary for your child. These can help prevent falls and bumps when your child is learning to walk and becoming more active.
- ✓ Begin to plan for your child's active life. Become familiar with NHF's "Playing it Safe" booklet. Consider swim lessons and other "parent and me" opportunities.

Understand the Genetics of Your Child's Bleeding Disorder

- ✓ Learn about the genetics of your child's bleeding disorder by talking with a genetic counselor or other HTC team staff. Evaluate whether other family members could benefit from being tested to determine if they are carriers or could be affected by a bleeding disorder.

If you have signs or symptoms of a bleeding disorder, consider getting checked by an adult hematologist. Ask your HTC team for a referral.

The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for bleeding and clotting disorders and to preventing the complications of these disorders through education, advocacy, and research. Its programs and initiatives are made possible through the generosity of individuals, corporations, and foundations, as well as through a cooperative agreement with the Centers for Disease Control and Prevention (CDC).

The contents of this brochure are the sole responsibility of the authors and do not necessarily represent the official views of the CDC and other NHF funders.

The information contained in this publication is provided for your general information only. It is not intended as a substitute for visiting with your physician, nurse, or social worker. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatments for specific individuals and in all cases recommends that you consult your physician or local treatment center before pursuing any course of treatment.

For more information or for help, please contact HANDI, NHF's informational resource center at **800.42.HANDI/800.424.2634** or e-mail **handi@hemophilia.org** or go to: **www.stepsforliving.hemophilia.org**.

Additional parenting resources can be found online: **www.cdc.gov/parents**.

Acknowledgements

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von Willebrand Disease

Piecing together the VWD puzzle



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders



The National Hemophilia Foundation (NHF) would like to thank the members of the working group that independently developed this brochure: Jeanette Cesta, National Bleeding Disorder Educator; Jessica Graham; James Hammel, MD, MA, MSc, FAPA; Debbie L. Nelson and Katherine Rosenblatt, LMSW.

The information contained in this publication is provided for your general information only. NHF does not give medical advice or engage in the practice of medicine. NHF under no circumstances recommends particular treatment for specific individuals and in all cases recommends that you consult your local physician or treatment center.

Just diagnosed with VWD?

Now what?

A diagnosis of von Willebrand disease, or VWD, can be scary, but it can also feel like all the pieces of a puzzle are finally in place. Your new diagnosis means that now you can get the care you need to control your symptoms, like bleeding or bruising. VWD is a genetic disorder caused by a missing or defective clotting protein in the blood called von Willebrand factor (VWF). VWF is important because it carries and protects another clotting factor in the blood – factor VIII. Without VWF, factor VIII becomes rapidly destroyed in the bloodstream/circulation, resulting in low factor VIII levels. It also helps platelets stick to the blood vessel walls at an injury site. The amount of VWF circulating varies over time and with different stress levels or activities, which complicates diagnosis and management.



There are several different types of VWD: 1, 2 (with 4 subtypes: 2A, 2B, 2M, 2N) and 3.

Many new patients are unsure of their type, so ask your doctor to explain your type, its severity and proper treatment.

What should I expect and anticipate? (Your VWD Survival Guide)

You'll find support and the encouragement to live a happy, healthy life with VWD. Learn all you can about VWD, then educate others. Telling close friends and your family about your VWD (this is referred to as "disclosure") and be prepared for emergencies. Get connected to the National Hemophilia Foundation's bleeding disorders community, where you'll find support and encouragement.

Sometimes having VWD can seem overwhelming. Just take a deep breath and reach out for help when you need it. There are many resources and helpful people in your own community. Take things one step at a time, beginning with this VWD checklist:





VWD Checklist:



1. Annual or Biannual VWD Visit – individuals with VWD should schedule routine follow-up visits with a medical provider who can help you manage your symptoms. You may be referred to a hemophilia treatment center (HTC), a specialized healthcare center staffed by a team of doctors, nurses and other health professionals experienced in treating people with VWD, or you may see an independent hematologist. During the visit, treatment options may be discussed, as well as tests to make sure your treatment works to manage your symptoms. HTC staff can answer questions about insurance coverage, educate school staff and help you adjust to life with VWD. Visit your hematologist regularly, even if nothing has changed. That way you will be aware of any new tests, treatments or information that could help. Regular visits strengthen your relationship with your medical team and keep them updated on any changes in your life that may affect your treatment.





2. Schedule Routine Healthcare Appointments –

Keep up with routine healthcare appointments and screenings, and attend to other medical issues promptly. Don't let that cavity (a typically minor bleeding issue) turn into a root canal or extraction (typically a greater bleeding issue).

- a. Primary Care Physician/Pediatrician: All of your physicians should be aware of your VWD diagnosis. VWD needs to be addressed before any procedures can be done, because some medications should not be given to patients with VWD. If surgery is being considered, communication with your VWD provider is critical to ensure that a plan is in place to address any bleeding complications. In fact, many surgeons will not schedule surgery without clearance from your doctor.
- b. Dentist/Oral Surgeon: Without pretreatment, some dental care procedures, such as deep cleanings, can cause a mouth bleed. Further, your VWD diagnosis must be considered before tooth extractions or gum procedures can be performed. Give your dentist your VWD provider's contact information so that they may coordinate the procedures.



3. Be Prepared for Emergencies –

Keep a supply of your medications, have current and after hours contact information for your medical team or local ER readily available and maintain a support team of family members/friends who can help in an emergency. Have a plan in place and share it with caregivers so that when a medical situation occurs, everyone knows what to do.



4. Wear Medical Alert Identification – A medical alert

identification bracelet, necklace or dog tag, notifies emergency workers that the wearer has a medical condition and who to contact for details. It has room to inscribe specifics such as diagnosis and allergies, and has a number to call for further information. Some products even have the information stored electronically in the medical alert identification.



5. Request a Travel Letter – It is important to request

a travel letter (sometimes called an introduction letter) from your VWD provider. The letter includes information such as your diagnosis (VWD and type), treatment plan for both minor and major bleeds, a list of your allergies and contact information for your hematologist. It is helpful in emergency rooms, when traveling and at school.





6. Stay Physically Active – Physical activity is important for overall health and for your VWD as well. Talk to your VWD provider about which activities are safe for you, and what protective gear or treatment you need beforehand. If you or your child is active in sports, tell the coach about your VWD diagnosis, symptoms and treatment, and that your medical alert identification can safely be worn during practices and games.



7. Communicate with School/Childcare/After-school programs – The school or child care provider should be informed of your child’s diagnosis. The best way to communicate with your child’s school is through a 504 plan. 504 plans help guarantee that every child has access to equal education regardless of a medical issue. Ask your child’s school about setting up a 504 plan, which often includes a meeting with key school personnel (e.g., teachers, school nurse, coaches, bus driver). During the meeting you can educate the staff about your child’s VWD, discuss any possible issues regarding school activities, prepare an emergency plan, and request accommodations you and your medical team feel are needed. These might include:

- a. Immediate access to the school nurse and bathroom when needed.
- b. Medication storage/administration at school.
- c. Permission to carry and use a cell phone for a medical issue.
- d. Accommodations when traveling on field trips (medication, travel letter, etc.)

If your child’s school doesn’t use 504 plans, you can still ask for a meeting to discuss any accommodations your child may need at school.



8. Disclosure in the Workplace/College -

Talk with your HTC social worker about your rights and how to inform your workplace or college.

Visit: www.stepsforliving.hemophilia.org for more information.



9. Connect with Your Bleeding Disorders

Community - Getting involved with your bleeding

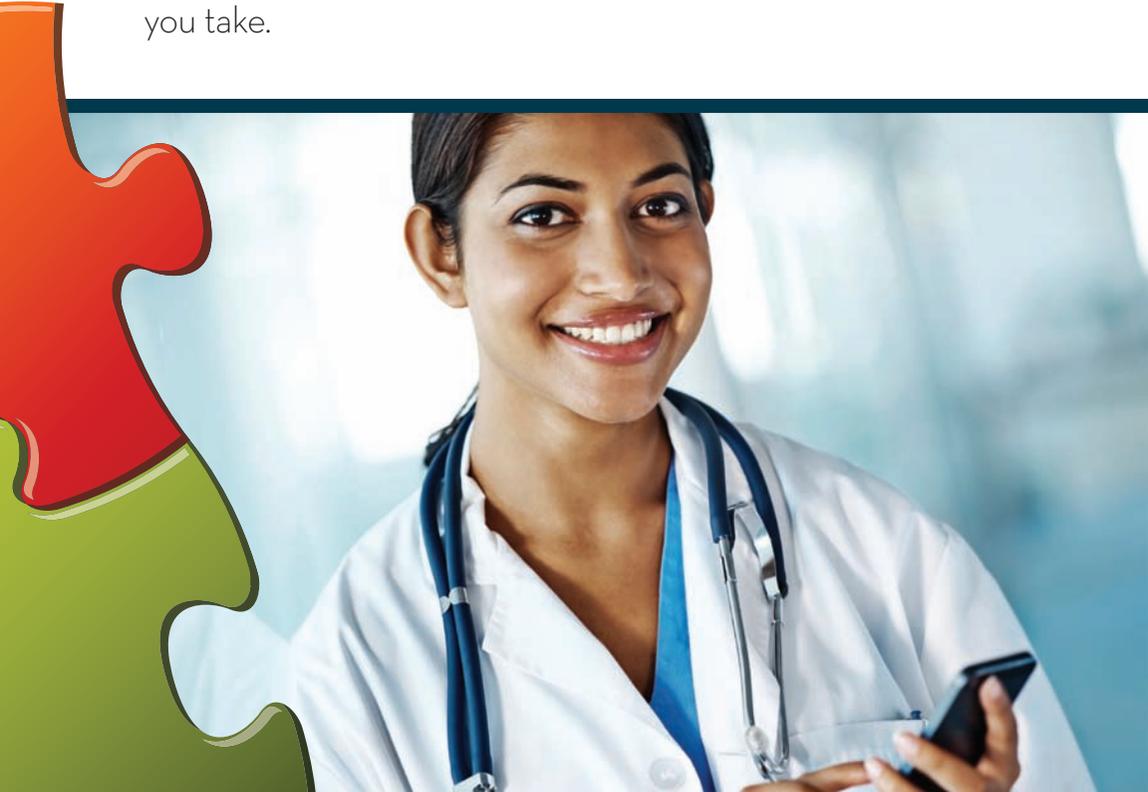
disorders community has many benefits. It will help you stay updated with the latest information on VWD, provide you with access to resources (educational materials, webinars, scholarships, etc.) and help you meet others who have a bleeding disorder through social and educational events. The best way to start is to contact your local chapter or HTC (see back of brochure).



What information do I need to share with my Hematologist/HTC?

When visiting your hematologist or HTC staff, come prepared with the following information:

- Your family history of a bleeding disorder. Document if your mother, father, siblings or children have or had bleeding problems.
- Prepare a list of the over-the-counter, prescription and herbal medications you take.
- Jot down your bleeding and bruising symptoms. If possible, make a list of recent bleeding or bruising episodes.
- The results of recent lab work.
- A list of your questions and concerns.



Know the symptoms, treat them and enjoy life

For Anyone: Frequent and prolonged nosebleeds, easy bruising and heavy bleeding after surgery or dental work are symptoms anyone with VWD may face. In more severe cases, bleeding into soft tissues and joints may occur. The treatment for VWD depends on the type and severity of the bleeding disorder, so talk to your hematologist/HTC to come up with the best treatment plan for you. Treatments are given by injection, nasal spray or pills.

For Women and Girls: Heavy menstrual bleeding is often a primary symptom for adolescent girls and women, but can be controlled with proper treatment. Women and girls can often participate in sports and other physical activities. They can progress safely through pregnancy, childbirth and menopause—all by staying engaged with their hematologist/HTC.

For Men and Boys: VWD is sometimes diagnosed at a later age in boys and men, even though it is equally common in men and women. The most common symptom in boys is frequent and prolonged nosebleeds. It is sometimes caught “by chance” by medical providers if there isn’t a clear family history, or if it isn’t recognized by care providers due to the challenges with diagnosis. VWD can cause significant problems among boys and men if not diagnosed and treated. Boys and men with VWD can often participate in many sports, and should stay engaged with their hematologist/HTC.



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7 Penn Plaza, Suite 1204, New York, NY 10001

For More Information and Support

For information about NHF and to find a local chapter:

www.hemophilia.org

For information on living with a bleeding disorder
through all life stages:

www.stepsforliving.hemophilia.org

Any other questions?

Call or email HANDI, NHF's information resource center:

800.424.2634 or **handi@hemophilia.org**

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