The National Hemophilia Foundation & Takeda are partnering to raise awareness of von Willebrand disease.

Brought to you by the National Hemophilia Foundation and Takeda

featuring actress and comedian
Alex Borstein
Letter to the Reader

Von Willebrand disease (most people call the disorder by its initials: V-W-D) is the most common inherited bleeding disorder, and it is also underdiagnosed.\textsuperscript{1-3} VWD affects up to 1\% of the US population—which means 1 out of every 100 people have VWD.\textsuperscript{1,2} That translates to up to 3 million Americans!

VWD is a lifelong disorder, but people with VWD have a lot of resources, like the National Hemophilia Foundation (NHF) and Takeda, to guide them on their journey. The NHF’s mission is dedicated to finding better treatments and cures for inheritable bleeding disorders and to helping prevent the complications of these disorders through education, advocacy, and research. Takeda is a patient-focused, values-based biopharmaceutical company committed to bringing better health and a brighter future to people worldwide. NHF and Takeda partner together to provide education and community support to assist in these efforts, such as with this guidebook.

This guidebook has been designed to be a helpful resource by providing detailed information about VWD, including common symptoms, diagnosis, and disease management; practical tips on caring for someone with VWD; and other resources for adults with VWD. As you read through this guidebook, remember VWD affects each person differently, so always contact a healthcare professional for specific guidance and to ask any questions about VWD. NHF and Takeda—through their resources and support programs—can help those with VWD take an active role in managing it.

Sincerely,

The National Hemophilia Foundation and Takeda
Message from Alex

My mother is a very low-level carrier of a bleeding disorder (BD), as am I, and my daughter has a BD. We have other close relatives who have BDs. It's, as they say, a family business. ;)

Taking an active role in the BD community wasn't a choice for me—it's a responsibility. One of our best lines of defense is education and awareness.

One of the things the BD community has taught me is that it's not just a physical disorder. I've seen how it literally “bleeds” into every aspect of life. Through my family's journey, I've learned these conditions have an emotional component, too, and all that can come with it. There can be a financial impact as well. Each individual has to be an advocate for their own care, or their child's care, and that can be a full-time job.

I've found it most difficult to advocate for my daughter because there's a sense that her BD is rare. Many men and women with BDs live their entire lives never being properly diagnosed. I believe there is a need for people to advocate for themselves if they think something is wrong. For example, if a woman experiences very heavy periods (a symptom of VWD), she should speak with her healthcare provider to determine if there is an underlying cause.

My response to anyone who suspects they might have a bleeding disorder? We know our bodies. We know when something is not right. It's especially important for healthcare professionals to trust their patients and work with them to find an accurate diagnosis and appropriate treatment plan.

—Alex Borstein
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What Is VWD?

As you’ve learned, VWD is an inherited bleeding disorder affecting up to 1 of every 100 people in the United States.\(^1\-^3\) So, what exactly is a bleeding disorder? Bleeding disorders are a group of conditions that result when blood can’t clot properly.\(^4\) This can mean unexplained nosebleeds, prolonged heavy menstrual periods, or bleeding longer after an injury, trauma, or surgery than a person without a bleeding disorder.\(^4\)

How does blood clot? Blood contains platelets (tiny blood cells) as well as proteins (or clotting factors) that work together to stop bleeding by causing the blood to clot. When a blood vessel is damaged and starts bleeding in a person without a bleeding disorder, a reaction begins. This reaction signals platelets to stick to each other and the injured area. This forms a clump in order to plug the hole and stop the bleeding. One of the clotting proteins is von Willebrand factor (VWF), a protein that acts like “glue” to hold the platelets to the wall of the injured blood vessel and form a plug.\(^5\)

VWF also carries and stabilizes factor VIII (factor 8), another important protein that helps blood clot. Hemophilia A is what the disorder is called when factor VIII is missing or is insufficient.\(^6\)

If the VWF is defective or missing, the blood’s ability to clot decreases, possibly leading to heavy or continuous bleeding. This condition is termed von Willebrand disease (VWD).\(^6\)
Three Types of VWD

There are 3 main types of VWD, with varying degrees of bleeding ranging in severity from mild, to moderate, to severe for each type. Each type may be treated differently, so it’s important to know the differences between them.

At a Glance: Types of VWD

<table>
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<th>TYPE OF VWD</th>
<th>HOW COMMON IS IT?</th>
<th>WHAT HAPPENS?</th>
<th>SIGNS AND SYMPTOMS</th>
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<tr>
<td>Type 1</td>
<td>60% to 80% of patients</td>
<td>Low levels of VWF</td>
<td>Usually mild</td>
</tr>
<tr>
<td></td>
<td></td>
<td>May also have low levels of factor VIII</td>
<td></td>
</tr>
<tr>
<td>Type 2</td>
<td>15% to 30% of patients</td>
<td>The VWF doesn’t work as it should, depending on the subtype</td>
<td>Can be mild to moderate, depending on the subtype</td>
</tr>
<tr>
<td></td>
<td>There are 4 subtypes: 2A, 2B, 2M, and 2N</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Type 3</td>
<td>5% to 10% of patients</td>
<td>Very little or no VWF and low levels of factor VIII</td>
<td>May be severe</td>
</tr>
</tbody>
</table>
Let’s take a closer look at the types of VWD. Type 1 VWD is usually the mildest and most common form of VWD. People who have type 1 VWD have low levels of VWF and may have low levels of factor VIII. Signs and symptoms may be mild.

Type 2 VWD has 4 subtypes: 2A, 2B, 2M, and 2N. In type 2, VWF doesn’t work as it should. The signs and symptoms can be mild to moderate, depending upon the specific problem with the person’s VWF.

**Subtypes of Type 2 VWD**

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<th>Type 2 VWD Subtypes</th>
<th>What Happens?</th>
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<tr>
<td><strong>TYPE 2A</strong></td>
<td>The VWF is not the right size and doesn’t “glue” the platelets to the blood vessel wall to plug the bleeding. This is the most common subtype.</td>
</tr>
<tr>
<td><strong>TYPE 2B</strong></td>
<td>The VWF becomes too active and “glues” to platelets in the bloodstream instead of “gluing” platelets to the wall where the bleeding is. This results in a shortage of platelets and VWF.</td>
</tr>
<tr>
<td><strong>TYPE 2M</strong></td>
<td>The VWF doesn’t stick to platelets at all, so a good plug can’t form.</td>
</tr>
<tr>
<td><strong>TYPE 2N</strong></td>
<td>The VWF works with the platelets the way it should, but it doesn’t carry or stabilize the other clotting protein—factor VIII—the way it should, so factor VIII levels are low.</td>
</tr>
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</table>
Type 3 is very rare and is the most severe form of VWD. People who have type 3 VWD usually have very little or no VWF and low levels of factor VIII. Symptoms may be severe and can include spontaneous bleeding episodes, often into joints and muscles.

_Early diagnosis is important. With the proper treatment plan, people with all types of VWD may be able to live normal, active lives._

**Is It or Isn’t It?**

*Signs and Symptoms of VWD*

_Every person with VWD is unique; even 2 people who are the same type may have very different experiences. Since symptoms can be very mild, especially for people with type 1 VWD, many people with VWD may not even know they have the disorder. In fact, research has shown that 9 out of 10 people with VWD have never been diagnosed!*

The most common symptom of VWD is abnormal bleeding, but people with type 1 or type 2 VWD may not have significant bleeding problems until a major surgery, dental procedure such as removing a tooth, or an injury. In the case of females with VWD, heavy _menstrual periods_ and childbirth with abnormal bleeding can be signs of VWD.

Type 3 VWD can cause major bleeding in infancy and childhood.

Again, an important thing to remember is that VWD affects everyone differently...even if they have the same type.
At a Glance: Common Signs of VWD

**FREQUENT OR HARD-TO-STOP NOSEBLEEDS THAT:**

- are spontaneous or start without an injury
- last more than 10 minutes
- occur frequently (5 times a year or more)
- need packing, or need to be cauterized, to stop bleeding, perhaps requiring a trip to a healthcare professional

**EASY BRUISING:**

- occurs frequently (1 to 4 times per month)
- occurs with little or no injury
- bruise has a raised bump and is larger than a quarter

**HEAVY OR LONGER THAN NORMAL BLEEDING:**

- during and after invasive procedures, such as dental procedures and surgery
- after a cut or injury to the skin
- during menstrual periods
- during or after childbirth
Symptoms in Women with VWD

Although VWD occurs equally in women and men, menstrual periods, pregnancy, and childbirth provide more opportunities for women with VWD to have increased bleeding.\textsuperscript{11}

For women with VWD, heavy menstrual bleeding is often the most common initial bleeding symptom.\textsuperscript{12} In some cases, even with other bleeding symptoms, it can take many years from the first symptom of heavy menstrual bleeding until a diagnosis of VWD.\textsuperscript{13,14}

Women should be aware of heavy menstrual periods with\textsuperscript{1,15}:

• bleeding that lasts for more than 7 days
• flooding or gushing of blood that limits activities
• passing of clots bigger than a quarter
• the need to change a tampon or pad every hour or more often on heaviest days, or use both tampons and pads together

Women with VWD are also at risk for heavy bleeding after childbirth—especially delayed bleeding, where it may stop and start again.\textsuperscript{1,16}

Early diagnosis is important and helpful for appropriate treatments. Without medical management, women with bleeding disorders may experience serious episodes of bleeding due to their condition.\textsuperscript{17}
Who Is at Risk for VWD?

The main risk factor for VWD is having a family history of it. VWD is usually passed to children through the genes of the parents. That is why it is often called an “inherited” disorder.²

If one parent carries the gene or has the disease—even if they don’t have symptoms—the child has a 50% chance of inheriting type 1 or type 2 (except 2N) VWD.⁶

Type 3 and type 2N are inherited only if both parents carry the gene or have the disease.⁶

In each of these cases, the child’s symptoms may be different from those of the parents.⁶
How Is VWD Diagnosed?

VWD can be hard to diagnose.\(^{18}\) Signs and symptoms are just one piece of the puzzle.\(^ {7}\)

As you learned earlier, since symptoms can be very mild—and differ between individuals—many people with VWD may not even know they have the disorder. This isn’t surprising, as people with type 1 or type 2 VWD may not have major bleeding problems until surgery or a major trauma or injury.\(^ {10}\) But since type 3 VWD can cause major bleeding in infancy and childhood, it is almost always diagnosed when a person is very young.\(^ {6,9}\)

VWD affects women and men equally,\(^ {2}\) and it is often missed until an injury or invasive procedure causes unusual bleeding. More women are diagnosed with VWD due to more apparent symptoms such as heavy bleeding during menstruation and unusual bleeding during childbirth.\(^ {11}\)

When you have VWD, you have to take every injury seriously.

Working with the doctor, I’ve learned how to take precautions. For example, when I was having surgery to remove a growth on my hand, I took medication before and afterward to prevent bleeding.

—Ryan, Person with VWD
How Is VWD Diagnosed? (continued)

**Physical Exam:** During a physical exam, the healthcare professional will look for bruising, petechiae (small red or purple spots caused by bleeding under the skin), and other evidence of recent bleeding, as well as focus on findings that may suggest other causes of increased bleeding, such as evidence of liver disease (for example, jaundice, or yellowing of the skin or whites of the eyes) or signs of anemia (low red blood cell count).^7

**Medical History:** Since VWD is usually an inherited disorder, the healthcare professional will take a medical history of the patient and the patient’s family and may ask questions about unusual bleeding in both. Sometimes type 1 and most of type 2 can be caused by a spontaneous mutation, so there isn’t a history of bleeding in a family,^19 or sometimes family members haven’t shared their bleeding history with anyone else. However, it is still important for the patient to share as much information as possible with the healthcare professional to help him/her make the correct diagnosis.^7
Blood Tests: Several blood tests are used to make a diagnosis of VWD. Routine blood tests often give normal results, which is why the person’s history of bleeding is so important.

Because a person’s VWF and factor VIII levels can vary at different times due to things like stress, exercise, age, and pregnancy, testing is often repeated. Blood tests may include:

- **VWF antigen**, which measures the amount of VWF in the blood
- **VWF ristocetin** (ris-to-SEE-tin) cofactor activity, a test that shows how well VWF works
- **Factor VIII clotting activity**, which checks the clotting activity of factor VIII; as you learned earlier, some people who have VWD have low levels of factor VIII activity, while others have normal levels
- **VWF multimers**, a test done if one or more of the first 3 tests is abnormal; it shows the structure of the VWF and helps the healthcare professional diagnose what type of VWD the person has
- **Platelet function test**, which measures how well the platelets are working

If the healthcare professional ordering the tests is the primary care professional, depending on the results, he/she may refer the patient to a hematologist—a doctor who specializes in bleeding disorders—or to a hemophilia treatment center (HTC) for diagnosis and follow-up.
What Is a Hemophilia Treatment Center?

A HTC is a specialized healthcare center that provides comprehensive care to people with bleeding disorders, including VWD. A team of healthcare professionals such as hematologists, nurses, and other health professionals (for example, social workers and physical therapists) who are experienced in treating people with bleeding disorders are brought together in these specialized healthcare centers to provide comprehensive care. They will also help to identify dentists and orthopedists (specialists in disorders of bones and joints) who are familiar with treating people with VWD.

The HTC is a valuable resource for the person with VWD. In addition to the care they provide, and referrals to medical professionals, they will also connect the person with VWD to various community groups that provide support and education for families.

The Centers for Disease Control and Prevention (CDC) maintains a list of HTCs nationwide so you can find one near or in your community.

Once you know, you can take proper precautions and get treatment. If you don’t know, you could be playing with fire.

—Ryan, Person with VWD
Treatment Options for VWD

Treatment for VWD is based on type and severity. Most cases are mild or may require treatment before surgery, dental procedures, or in the event of an accident.

Depending on the type of VWD, medicine will be used to:

- **Replace VWF**—This is called *replacement therapy* and can be used for those who need treatment.\(^6\)
- **Stimulate the body’s ability to increase naturally occurring VWF and factor VIII**—This is called *non-replacement therapy*.\(^6\)
- **Control heavy menstrual bleeding in women**—This type of treatment can be hormonal and depends on the circumstances and the type of VWD.\(^7,18\)
- **Stabilize blood clots**—These medicines are called *antifibrinolytics*.\(^6\)

  - Sometimes the medicines are drugs applied to cuts or nosebleeds. These are *topical agents* or sponges that are used to seal minor bleeding sites.\(^6\)
Special Circumstances
Preparing for Dental, Medical, and Surgical Procedures

When possible, plan ahead for any type of procedure! It is important to let the healthcare professional performing the procedure know that you have VWD well before the procedure. You or he/she should contact your hematologist or healthcare professional ahead of time, too. Bleeding that occurs with surgery or a procedure may last much longer in a person with VWD, which can slow wound healing.

Planning ahead—and proper management before, during, and after a procedure—may help to prevent heavy or unnecessary bleeding.
Pregnancy, Childbirth, and VWD

With advance planning, it is possible for women with VWD to have a successful pregnancy.\textsuperscript{21,22} Family planning counseling is often provided at HTCs, so people with VWD should take advantage of these resources before, during, and after a pregnancy.\textsuperscript{21}

Although levels of VWF and factor VIII tend to increase during pregnancy in women with VWD, it’s common for women with VWD to have heavy bleeding for an extended period of time after delivery.\textsuperscript{22}

Women with VWD should be under the care of a hematologist and an obstetrician who specializes in high-risk pregnancies. These specialists need to be part of the care team before and throughout the pregnancy and delivery, and for a period of time after delivery.\textsuperscript{22}

Women with VWD should also plan on delivering in a facility that has appropriate support for women with VWD—including bleeding disorder specialists, labs, a pharmacy, and a blood bank.\textsuperscript{22,23}

With my first child, I had a tear and bleeding. With my second son, I had a C-section which caused bruising. But my healthcare team knew about my VWD, so they were able to handle those problems right away.

It’s really important to ask questions and keep asking until you’re sure you understand the answers. One of the first questions to ask is whether the healthcare team you’re seeing is familiar with how to treat bleeding disorders.

—Kelly, Person with VWD
Tips for Patients and Caregivers

Keep a first aid kit handy and up to date! In the kit, be sure to include:

- Instant cold packs
- Compression bandages
- Adhesive bandages
- Gauze and surgical tape
- Prescribed medications
- Contact information for your healthcare professional, HTC, and local hospital

NHF recommends everyone with a bleeding disorder also wear medical ID, such as a medical alert bracelet or necklace.

Tips for Dealing with Medical Emergencies

Tell the medical and nursing staff that you have VWD and what it means regarding your risk of unusual bleeding.

Keep contact details of your hematologist or regular healthcare professional handy. You may wish to contact him/her before you seek emergency treatment or ask the healthcare professionals where you are getting care to contact your hematologist or regular healthcare professional for advice.
Plan ahead! Most HTCs will give you a “travel letter” with your plan and key medical contacts that you can share with healthcare professionals in an emergency room.\(^{24}\)

Also, be sure to have an ICE (In Case of Emergency) number in your mobile phone. Always carry or wear medical identification information.\(^{25}\) In an emergency, even if you are conscious, you may not be well enough to communicate clearly. Let the emergency contact know you have VWD, what it means, and what to tell someone in case you are unable to communicate.

If you are prescribed medication, take it with you.\(^{26}\)

**Travel Tips**

Let your hematologist or regular healthcare professional know if you are traveling out of state or overseas. Always carry and/or wear medical identification information.\(^{26}\)

Look up the names, addresses, and phone numbers of hematologists or healthcare professionals and hospitals where you will be traveling.\(^{26}\) To locate HTCs in the United States, access the CDC website at [https://www.cdc.gov/ncbdd/hemophilia/treatment.html](https://www.cdc.gov/ncbdd/hemophilia/treatment.html) for the HTC directory.

Takeda and NHF have guides for travel and vacation planning that can be found at [https://stepsforliving.hemophilia.org/step-up/travel](https://stepsforliving.hemophilia.org/step-up/travel) or [https://www.bleedingdisorders.com/living-well/travel](https://www.bleedingdisorders.com/living-well/travel).

For international travel, the World Federation of Hemophilia (WFH) has a Global Treatment Centre Directory listing treatment centers and hemophilia organizations worldwide.\(^{26}\) They also have tips for travelers at [https://www.wfh.org/en/page.aspx?pid=902](https://www.wfh.org/en/page.aspx?pid=902).
Take Control: Healthy Living with VWD

While living with VWD has its challenges, living a healthy lifestyle is an important way to manage this disorder so you can feel your best. A person with VWD can help to optimize her or his wellness—not just medical wellness, but physical, nutritional, and emotional wellness.

Get Moving!

Regular exercise and being physically active can be a great way to keep joints and muscles moving the way they should. Exercise and even sports are not only possible for people with VWD but, depending on the type and each individual’s circumstances, appropriate activity is encouraged. Whether it’s sports like tennis or exercise like weight lifting, walking, or yoga, people with VWD just need to find out what works for them! NHF has great resources on physical activity at its “Steps for Living” website: https://stepsforliving.hemophilia.org/resources/physical-activity.

In addition to improving levels of cardiovascular and physical fitness, being active can increase flexibility and strength.

Being active may also:

- improve your quality of life
- help reduce feelings of anxiety and depression
- help with weight loss and fatigues

For more resources about being physically active with a bleeding disorder, go to the Steps for Living website: stepsforliving.hemophilia.org or BleedingDisorders.com: https://www.bleedingdisorders.com/living-well/exercise.
Eat Healthy!

A healthy diet is also part of a healthy lifestyle for a person with VWD.\(^{29}\)

We know exercising several times a week can have a positive impact on health, including for those with VWD. Balancing exercise with good nutrition is especially important for people with a bleeding disorder like VWD.

Try to make healthy eating a regular habit. See if you can make half your plate nutritious foods like fruits and vegetables. A diet rich in whole grains, fruits, and vegetables—but low in fat, sugar, and sodium (salt)—will help provide you with nutrition to keep you at your best while living with your bleeding disorder.\(^{29}\)

Don’t try to make up for poor nutrition by taking vitamins, supplements, or herbs! Some of these may increase or decrease bleeding or clotting times, so always talk with your healthcare professional before taking anything you were not prescribed...even if it is available over the counter.\(^{29}\)

To learn more, visit: https://www.bleedingdisorders.com/living-well/diet.

Breathe Deep and Get Some Shut-Eye!

In addition to exercise and good nutrition, stress reduction and adequate rest and sleep will also help you feel your best.\(^{30}\)

Mindful meditation, appropriate physical activity and deep breathing can help you manage stress. But if you are still having trouble managing your stress levels—whether due to VWD or other issues—be sure to contact your healthcare professionals. They want to help!
Conclusion

The good news is, most people with VWD live a full and active life!

- VWD is the most common bleeding disorder caused by a missing or deficient clotting protein called von Willebrand factor
- Report any unusual bleeding to a healthcare professional
- It is important to get an early and accurate diagnosis
- Review your medical and family history with your healthcare provider if you are experiencing symptoms
- Be an advocate for yourself and those around you
- Always consult your healthcare team with any questions; they are there to help you
- Stay active
- Eat a healthy diet including whole grains, fruits, and vegetables
- Get plenty of rest and manage stress
- Plan ahead for travel or activities

There is a large community in support of people with VWD. In fact, you can connect with other families affected by bleeding disorders in your area through NHF’s chapter network by going to this site: https://www.hemophilia.org/Community-Resources/Chapter-Directory.

With knowledge comes the power to take control and manage VWD, so take advantage of all the resources available, starting with your healthcare professionals and the National Hemophilia Foundation.
I think wanting to bring levity to some of those scary, tense, anxiety-ridden moments made me do things to get a laugh. I saw that it healed, I saw that it helped, and it got me attention. And so I think I cultivated that for the rest of my life.

—Alex
Glossary

**Cardiovascular**: pertaining to the heart and blood vessels

**Cauterize**: destroying abnormal body tissue or skin by burning or scarring it with heat, cold, electric current, ultrasound, or chemicals; this seals the blood vessels and builds scar tissue to help prevent bleeding

**Comprehensive care**: the concept of comprehensive care is to treat the whole person and family through continuous supervision of all of the medical and psychosocial aspects of bleeding disorders

**Diagnose**: to identify or recognize a disease

**Fatigue**: the condition of being tired in body or mind

**Gene**: a tiny section of a chromosome; genes cause certain characteristics—such as eye color, hair color, and even diseases—to be passed on from parent to child

**Inherit**: to receive a trait through a parent’s genes

**Menstrual period**: the monthly discharge of blood and mucus from a non-pregnant female’s uterus; also known simply as a “period”

**Packing**: filling a wound with gauze, sponge, or other material to help stop bleeding

**Topical agent**: medicine that is applied directly to the skin or a wound; for example, a cream or ointment

Resources

**American Society of Hematology** | https://www.hematology.org/

**CDC** | https://www.cdc.gov/ncbddd/vwd/facts.html

**National Hemophilia Foundation** | https://www.hemophilia.org/Bleeding-Disorders/Types-of-Bleeding-Disorders/Von-Willebrand-Disease

https://www.hemophilia.org/Community-Resources/Chapter-Directory


https://betteryouknow.org

**Takeda** | https://bleedingdisorders.com

The National Hemophilia Foundation (NHF) and Takeda strive to provide educational and medically accurate information to the bleeding disorders community. For individualized healthcare advice, always contact your healthcare provider.

Thanks to our development and production partners:
DISCLAIMER

This guidebook is intended for informational purposes only, with the understanding that no one should rely upon this information as the basis for medical decisions. NHF’s Medical and Scientific Advisory Council (MASAC) recommends that product and corresponding treatment regimen used by an individual should remain a decision between patient and healthcare provider. Any actions based on the information provided are entirely the responsibility of the user and of any medical or other healthcare professionals who are involved in such actions.
PROGRAM PARTNERS

NATIONAL HEMOPHILIA FOUNDATION

The National Hemophilia Foundation (NHF) is dedicated to finding better treatments and cures for inheritable bleeding disorders and to preventing the complications of these disorders through education, advocacy, and research. Established in 1948, the NHF has chapters throughout the country. 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).

TAKEDA

At Takeda, we are tireless in our pursuit of a world free of bleeds. Through our 70-year commitment to the bleeding disorder community, as Baxalta and Shire, and now as Takeda, we believe that we can continue to develop and deliver innovative and transformative treatments for people living with bleeding disorders such as von Willebrand disease. Takeda is dedicated, more than ever, in our efforts to offer a wide range of educational programs and support to help patients throughout their treatment journey.

LET’S MAKE TODAY BRILLIANT.

Visit ThinkVWD.com to learn more and see a video featuring actress and comedian Alex Borstein