HEMOPHILIA
OUTREACH CENTER

Caregiver Guide

FOR YOUR CHILD WITH A BLEEDING DISORDER

Timeline for Bleeding Disorders

1803-1973

1803

Dr. John Otto identified a hereditary bleeding disorder affecting males and passed down by healthy females.

1819

Queen Victoria is born, later reported to be the carrier for hemophilia B or the "royals disease".

1828

Term "haemorrhaphilia" first used. Later shortened to "haemophilia."

1840

First whole blood transfusion given at hospital in London to treat hemophilia

1920s

Hospital-based plasma transfusions first used for treating hemophilia

1924

Erik von Willebrand identifies a bleeding disorder, later called von Willebrand disease (VWD)

1937

Researchers discover Factor VIII clotting protein

1948

National Bleeding Disorders Foundation (NBDF) opens as The Hemophilia Foundation, Inc.

1952

Researchers describe what is now called factor IX clotting protein

1954

NBDF establishes a Medical Advisory Council, later called Medical and Scientific Advisory Council

1955

First infusions of factor VIII in plasma form

1957

Researchers in Sweden identify von Willebrand factor as the cause of VWD

1958

First use of prophylaxis for hemophilia A

1963

World Federation of Hemophilia is founded

1965

Dr. Judith Graham Pool discovers cryoprecipitate

1968

First plasma derived FVIII concentrate available

First man on the Moon

1969

First Hemophilia Summer Camp Opens – Michigan Camp Bold Eagle

1970

Second Hemophilia Summer Camp Opens – Oregon

1970s

Freeze-dried plasma-derived factor concentrates available.

1973

The Hemophilia Act passes through Congress, allowing federal funding for HTCs.

Over 140 centers operate nationwide today!

We're So Glad You're Here

Finding out your child has a bleeding disorder can stir up so many emotions, and it's okay to feel angry, heartbroken, or even to grieve the life you imagined for your child. Those feelings are real and completely normal. Give yourself permission to sit with them and take the time you need. You don't have to have it all figured out right now. Just know you're not alone. There's a whole community here to walk beside you, listen when it's hard, and remind you that hope and joy still have a place in your family's story.

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Caregiver Guide

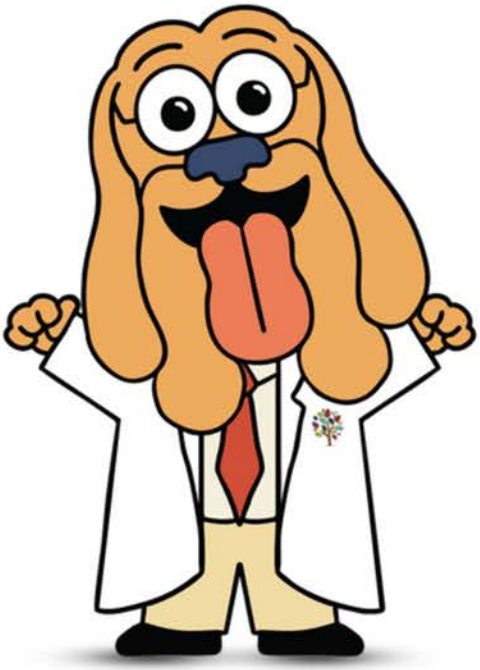
FOR YOUR CHILD WITH A BLEEDING DISORDER

Meet our HOC Mascots

Ivy and Buddy are here to help families navigate the world of bleeding disorders with confidence and care. Throughout this Caregiver's Guide, Ivy and Buddy will be your trusted companions, leading you through helpful tips and activities to empower you and your child on this journey.

Hi, I'm Ivy!

Hi friends! I'm Ivy, a little porcupine finding my way through life with a bleeding disorder. It's a big world out there, and sometimes it feels overwhelming—but **I've learned** that I don't have to face it alone. In fact, I discovered that courage comes from leaning on those who care about you! With my family, the supportive team at HOC, and my new friends in the bleeding disorder community, I'm ready to take on each challenge. Let's stick together and tackle this adventure one step at a time!



Hi, I'm Buddy!

Hello! I'm Buddy, a wise old bloodhound who loves to sniff out knowledge. Bleeding disorders might seem tricky, but with a bit of patience and teamwork, we can solve the challenge together. Here at HOC, you'll find a community that's ready to guide you and cheer you on. Got questions? That's paw-some—curiosity is the first step to confidence. **Let's learn and grow together! We'll turn challenges into opportunities for growth!**

Section 01

The Impact of Bleeding Disorders on the Family

The Impact of bleeding disorders on the family

A diagnosis of a bleeding disorder in a child impacts the entire family whether it is anticipated or out of the blue. It may heighten emotions that can add to the usual challenges of raising a child. In addition to the stress that a diagnosis of a bleeding disorder brings to families, associated conditions, such as iron deficiency and potential musculoskeletal complications can add more stress and further impact quality of life for the family.

You are not alone: Support and Information to help you and your family

It is important that families with bleeding disorders know that they are not alone. Many families struggle after receiving a diagnosis, but the Hemophilia Outreach Center is here to support you every step of the way. The Bleeding Disorder Caregiver Guidebook is a home-based resource designed to provide support and education to assist families through their lifetimes.

The Bleeding Disorder Caregiver Guidebook contains useful information and resources, available to you from The Hemophilia Outreach Center, to help you navigate this journey successfully. It is important to understand that The Bleeding Disorder Caregiver Guidebook is not a tool for diagnosis or a replacement for medical evaluations. It is a place to discover ideas, strategies, and suggestions that will help you anticipate and meet the demands of your family and child.

What to expect from a child with a bleeding disorder

Your child with a bleeding disorder looks and acts like any other child. The Hemophilia Outreach Center encourages your child to lead a life as similar as possible to any other child. Children explore and live active lives, and accidents may happen. Educating yourself and your child on how to identify an active bleed, or a potential bleed and when to contact HOC for evaluation and treatment are some of the many tools our caring staff will provide you. Remember we are by your side every step of the way!

Parenting Strategies

After a child has been diagnosed with a bleeding disorder, it is common for the family to feel overwhelmed. Parents may find it challenging to keep their typical routine at home while adjusting to meet their child's needs. The affected child's siblings will also be impacted by a new diagnosis and may find it difficult to understand. Here are a few parenting strategies that may help and keep you from becoming overly stressed:

LEARN ABOUT YOUR CHILD'S DIAGNOSIS—KNOWLEDGE IS POWER!

- Frequent conversations and reading children's books about their bleeding disorder educates and empowers you and your child
- HOC can help you with age-appropriate resources and tools to allow your child to learn and grow at any stage of their life

DEVELOP A ROUTINE. STRUCTURE AND ORGANIZATION CAN BE COMFORTING.

FAMILIARIZE YOURSELF WITH ALL THE PROGRAMS AND RESOURCES AT HOC

REMEMBER THAT YOU ARE NOT ALONE

- Consider attending one of HOC's community groups to talk with other families that have children with bleeding disorders. These families may still be learning (just like you) or have already walked a similar path and have valuable information to share with you. Mentorships for your child and your family can make a difference in the understanding of their bleeding disorder. Please contact HOC to be assigned to a mentoring family.

Encouragement & Advice for Caregivers

Caring for a child with a bleeding disorder comes with unique challenges, but you are not alone. While your focus is often on your child's well-being, it's important to also take care of yourself. Finding balance, seeking support, and celebrating small victories can make a world of difference. Here are some words of wisdom and encouragement to remind you that you are doing an incredible job—one day at a time.

YOU ARE NOT ALONE

Lean on the bleeding disorder community, your HTC care team, and loved ones. There's always someone who understands and is willing to help.

TAKE IT ONE DAY AT A TIME

Some days will feel overwhelming, but remember, you don't have to have all the answers at once. Just focus on what's in front of you.

GIVE YOURSELF GRACE

Being a caregiver is a journey, and there's no perfect way to do it. You're doing your best, and that's enough.

CELEBRATE PROGRESS, NOT PERFECTION

Every small step forward is a victory. Whether it's mastering an infusion or gaining confidence in advocacy, recognize and celebrate these wins.

TRUST YOURSELF

No one knows your child better than you. Your intuition, love, and dedication make you the best advocate they could have.

Hello

Hemophilia Outreach Center

Welcome to the Family!

You may be experiencing feelings that you have no idea how to process: fear, anxiety, anger, disbelief and sadness, just to name a few. I am writing you to let you know you now have a community that can help with ALL of the above feelings. The Hemophilia Outreach Center not only saved my son's life (several times) but also assuaged my guilt and helped me to maintain my sanity (on countless occasions).

As a parent of a child with a bleeding disorder, I was overcome with anxiety and overwhelmed with anger and sadness. There was no history of a bleeding disorder in my family, so saying I was ill-equipped was an understatement. After my son was born, the blood tests that the hospital performed identified my son as a Type III VonWillebrand's child. As a matter of fact, they had left a voicemail telling me that my son had a "deadly blood disease". You can empathize, I'm sure, with utter shock and sheer terror in which I heard those words. This, however, would be the gist of how the NON-BLEEDING DISORDER world sees our children. I soon met with the doctors and staff of the HOC and realized this was NOT the case.

The HOC was created specifically for those with bleeding disorders, and not just the patient- but the family as well! Yes, a comprehensive clinic that is as specialized as a French Bakery is to fine pastries. The HOC is like nothing else I ever have encountered. They address the medical, financial, social, and familial needs of each patient. When my son reached school age, I was TERRIFIED of him being at school and him getting a bleed and the staff not knowing that he needed extra attention, just to live! The HOC came in and provided an in-service to every school he attended before the year started just to make sure ALL staff members were aware of what to do and how to facilitate his care. The HOC worked with me repeatedly until I was able to care for him, and then taught HIM how to infuse and care for his bleeding disorder himself.

My son is now a thriving 22-year-old in his last year of college, but his life, like your child's will be, was not easy by any means. Because of the HOC, we were given a community and staff of support no matter the time or the day. The Hemophilia Outreach Center is here for YOU and for your child!

I would like to personally welcome you to the one place that not only understands what you and your family needs but goes above and beyond on a daily basis to improve the quality of life for your child.

You got this —

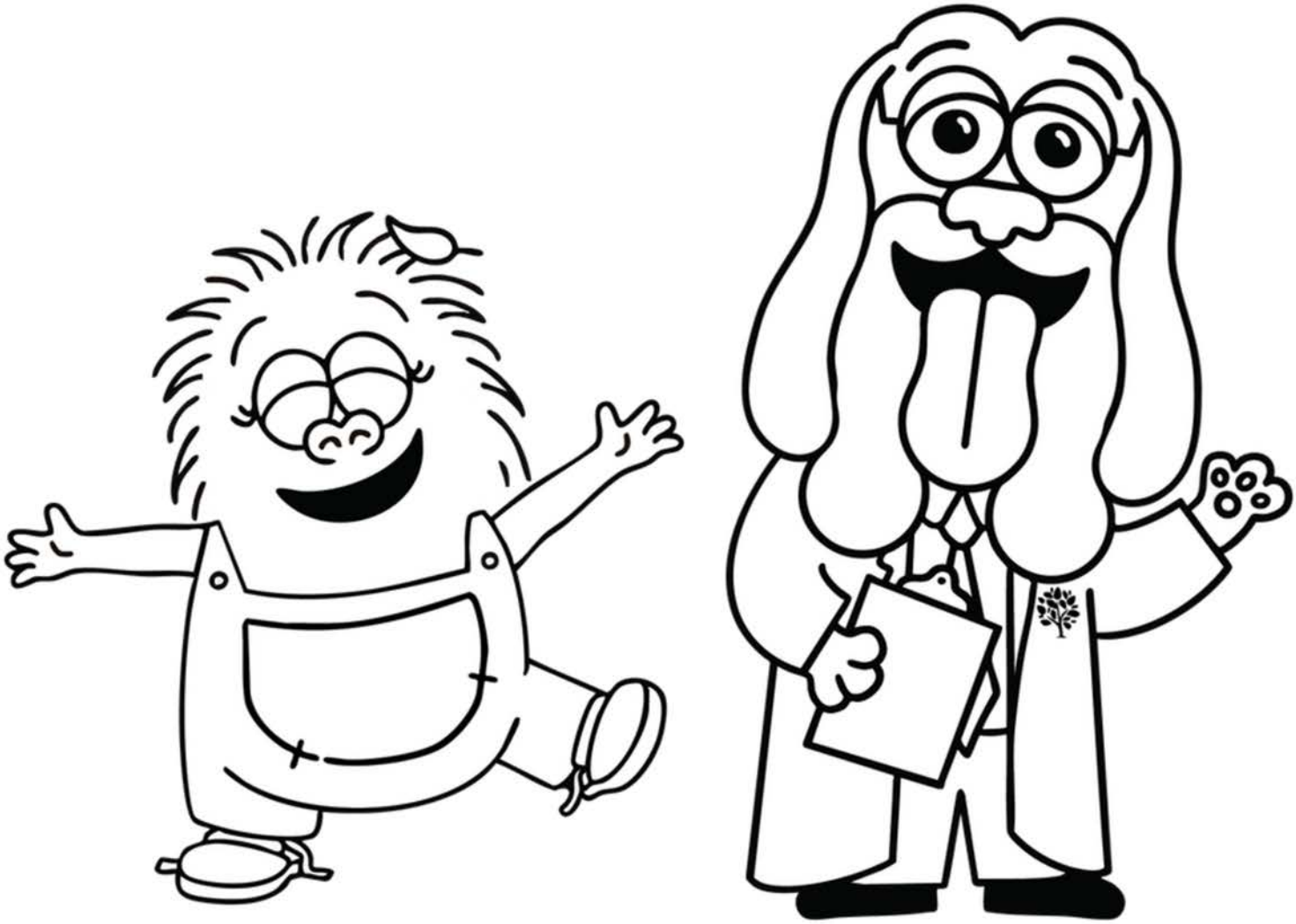
Christy F.

Print this page for your child!

Activity

Ivy and Buddy are here for you!

Print this page and color it in. When you're done, hang it in a place where you will see it, such as on your refrigerator.



Ivy

Buddy

Section 02

Understanding Bleeding Disorders

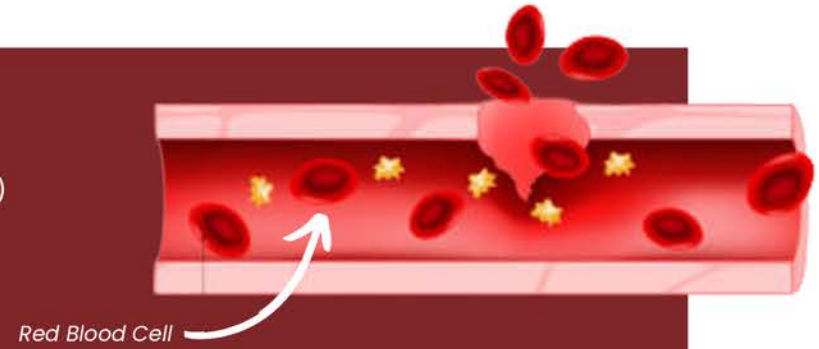
Glossary

Bleed	Internal or external bleeding, often spontaneous or from injury.
Blood Clot	A clump of blood that has changed from a liquid to a gel-like or semi-solid state to stop bleeding.
Bruising	Discoloration from bleeding under the skin; common with bleeding disorders.
Carrier	Someone who carries a bleeding disorder gene and may have symptoms.
Clotting Factor	A blood protein that helps stop bleeding.
Coagulation	The process where blood forms clots to stop bleeding.
Factor	Treatment that replaces missing clotting proteins.
Fibrin	An insoluble protein (does not dissolve in blood) formed during blood clotting that helps create a mesh to hold the clot together and stop bleeding.
Gene Therapy	A one-time treatment that helps the body make its own clotting factor.
HOC	Hemophilia Outreach Center, your local care and support center.
HTC	Hemophilia Treatment Center, a clinic for specialized bleeding disorder care.
Inhibitor	An immune response that blocks factor from working properly.
Infusion	Giving medicine or factor through a vein using a needle.
Port	A small device under the skin to make infusions easier.
Prophy	Prophylaxis: Regular preventive treatment to reduce bleeds.
Thrombin	Enzyme that helps form blood clots by converting fibrinogen into fibrin.
vWD	Von Willebrand Disease, a common inherited bleeding disorder.

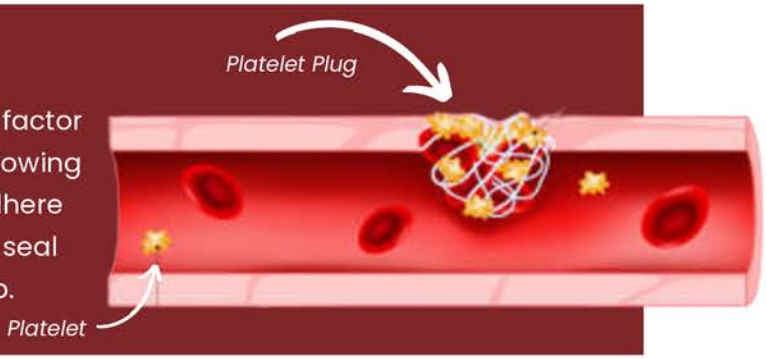
Blood Clotting Process

Bleeding occurs when a blood vessel—such as an artery, vein, or capillary—is cut or injured, either internally or externally. The body initiates a three-step process to form a clot or coagulation and stop the bleeding:

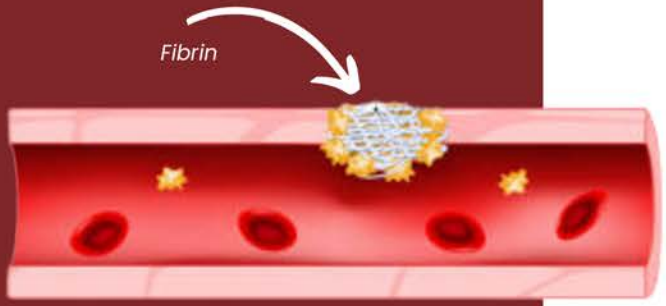
VASOCONSTRICTION:
The blood vessel constricts (tightens) to minimize blood loss at the site of the injury.



PLATELET PLUG FORMATION:
When an injury occurs, Von Willebrand's factor lays down like velcro at the injury site, allowing sticky, round platelets to attach. They adhere to the damaged area, forming a plug to seal the hole temporarily like an internal scab.



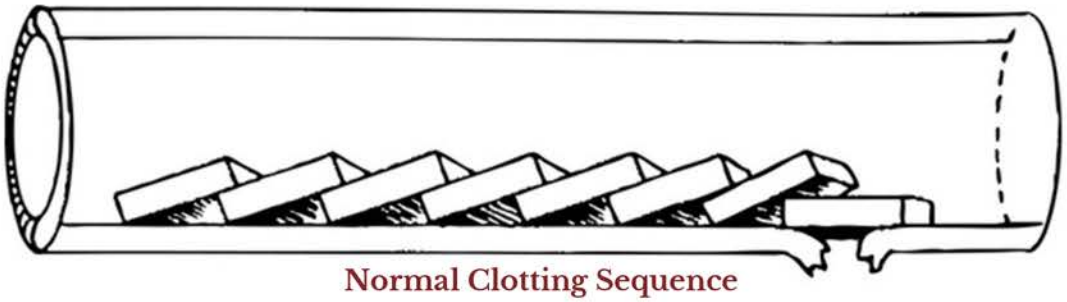
FIBRIN NET FORMATION:
Thirteen different protein clotting factors in the bloodstream work in a chain reaction to create a fibrin "net." This net stabilizes the platelet plug by forming a mesh over the wound, preventing further blood loss. Over time, the net and platelet plug harden, stopping the bleeding. Meanwhile, the blood vessel repairs itself by growing new cells over the injury site.



What is Factor?

Factor refers to proteins in the blood that help form clots and stop bleeding. There are 13 different clotting factors, and they work together in a domino-like sequence to form a blood clot when a blood vessel is injured.

Domino Sequence



Normal Clotting Sequence

Missing Factor

- Without one factor, the clotting system does not work appropriately.
- When an injury occurs that causes blood to flow ...
  - The blood vessel constricts to limit the blood flow at the plug site
  - The platelets are activated to stick together to create a plug
  - VWD factor helps the platelets stick to each other and the blood vessel wall
  - The clotting factors signal fibrin to be produced
  - The fibrin surrounds the platelet plug to form a fibrin clot

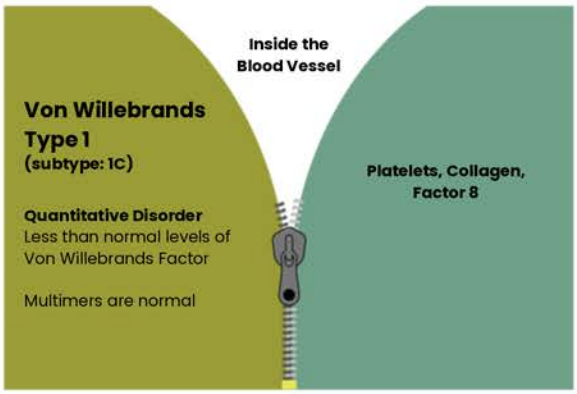
- **IN BLEEDING DISORDERS**
  - Hemophilia: The clot is not made or not made strong enough to stop bleeding
  - Von Willebrands: The platelet plug is not able to form

What is von Willebrand's Disease?

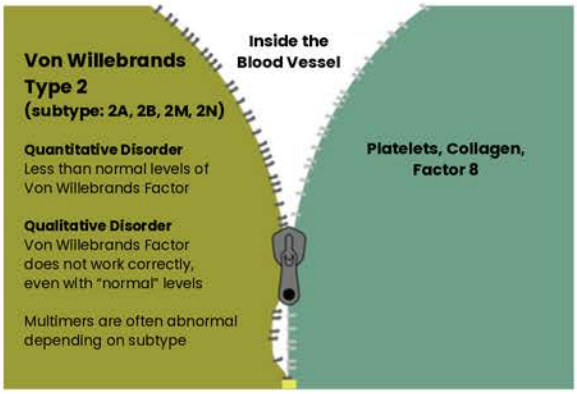
Von Willebrand Disease is a genetic bleeding disorder in which patients either don't have enough von Willebrand factor (vWF) or it doesn't work properly. Von Willebrand Factor is a protein in the blood that is important for forming clots. This protein acts like a sticky substance and helps platelets "glue" together to form a clot. Some people with vWF also may not have enough clotting factor VIII (8). Factor VIII is necessary when creating the plug that stops the bleeding. Without enough factor VIII, the plug cannot stay in place and do its job to stop bleeding.

vWD Type 1 is the most common form of vWD affecting 70-80% of those with vWD and it is considered the mildest. People with vWD Type 1 have less vWF in their blood than normal.

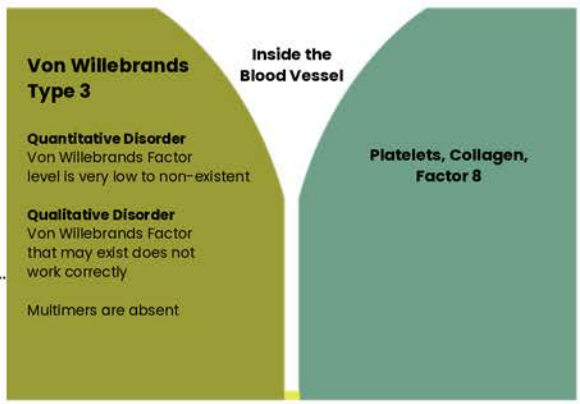
- **Type 1C:** vWD Type C has less than normal to near normal amounts of vWF, but the half-life of it is very short. This means it is used up extremely quickly in the body (we're talking lightning speed fast) to the point that it's virtually nonexistent.



vWD Type 2 is when your body makes vWF, but it doesn't work properly or there may also be decreased levels. There are several different forms of Type 2 vWD and they all have problems with the way vWF works. This can get technical, so if you desire more information, please ask your HOC nurse. Multimers are the "glue" between factor VIII, platelets, collagen and vWF.



vWD Type 3 has similar symptoms to a patient with severe Hemophilia (bleeding can be spontaneous or trauma related and affect joints). There is little to no vWF and factor VIII for the body to use to stop bleeding.



Key:

Multimers (AKA: the zipper)=large proteins that help bind von willebrand factor to platelets, collagen, & factor 8

Signs and symptoms of von Willebrand Disease

Individuals with vWD may experience bleeds in muscles and joints but more commonly bleeding occurs in the nose, gastrointestinal tract (bright red blood in stool, black stool, red urine or coffee ground looking vomit) and female reproductive tract (potentially affecting periods and childbirth for example).

Longer bleeding from an injury

Nosebleeds that do not stop within minutes

Heavy or long menstrual bleeding

Blood in urine or stool

Easy bruising or lumpy bruises

The genetics behind von Willebrand Disease

vWD affects men and woman equally.

Type 1 and Type 2a can be inherited in two different ways. Autosomal dominant is when only one parent has the affected gene to pass on OR autosomal recessive is when both parents have the affected gene but don't have known symptoms and pass it on. Types 2b and 2m are both autosomal dominant. Type 3 is autosomal recessive.

Laboratory tests for VWD Glossary

Test	Purpose
von Willebrand factor antigen (VWF:Ag)	Measures the amount of VWF
Ristocetin co-factor and/or collagen binding activity (VWF:RCo and/or VWF:CB)	Measures the functional (working) activity of VWF
von Willebrand factor multimers	Provides a visualization of how well the VWF monomer (molecule) is multimerized (joined into chains)

What is Hemophilia?

Hemophilia is a genetic bleeding disorder in which patients don't have enough or any of a specific protein clotting factor. Missing this clotting factor affects the sequence of events to form a clot causing the bleeding to last longer. Normal clotting factor levels are 50-150%. Mild Hemophilia has a factor level of 6-49%. Bleeding tends to only occur after a major injury, surgery, or dental work. Moderate Hemophilia has a factor level of 1-5%. Bleeding may be spontaneous, but it tends to occur after an injury, surgery, or dental work. Severe Hemophilia has a factor level less than 1%. Bleeding can occur spontaneously. It also occurs after injuries, surgery, or dental work.

Hemophilia Types

TYPE A	**Type B**	**Type C**
Hemophilia A lacks Factor VIII (8)	Hemophilia B lacks Factor IX (9)	Hemophilia C lacks Factor XI (11)
MOST COMMON	**LESS COMMON**	**LEAST COMMON**

What does it mean to be a carrier?

A carrier is someone who carries the gene for hemophilia but may not have symptoms themselves. Hemophilia is passed down through the X chromosome.

- If a male has hemophilia, all of his daughters will be carriers (these are called obligate carriers).
- If a female is a carrier, each of her sons has a 50% chance of having hemophilia, and each of her daughters has a 50% chance of being a carrier.

Signs and symptoms

Individuals with Hemophilia may experience bleeds in the head, nose, abdomen/gastrointestinal tract (bright red blood in stool, black stool, red urine or coffee ground looking vomit) and female reproductive tract (potentially affecting periods and childbirth for example). Most bleeds occur in the joints and muscles.

The genetics behind Hemophilia

Hemophilia affects men and woman, but primarily men. The gene is passed on the X chromosome (women have XX and men have XY). When the father has hemophilia, the daughters will be carriers (obligate), but the sons will not have hemophilia. When the mother is a carrier of the hemophilia gene, each child has a 50/50 chance of having hemophilia (male) or being a carrier (female). Women may also have levels that classify them as having mild hemophilia. Hemophilia can also occur without a family history. About 30% of newly diagnosed patients are classified as spontaneous mutations.

Levels of Severity in Hemophilia

Severe	Moderate	Mild
Factor Level <1%	Factor Level 1-5%	Factor Level >5%
Can bleed without injury	Can bleed with slight injury	Can bleed with bad injury or following procedures
May bleed 1-2 times per week	May bleed once per month or more	May never have a bleeding problem
Usually has joint problems	May have joint problems	Rarely has joint problems
Standard of care is Prophylactic Treatment	May be on Prophylactic treatment or treated On Demand only	Treated On Demand. Very rare prophylactic treatment is used.

Degrees of Severity

Normal
Factor VIII or IX activity
50-150%

Near Normal
Factor VIII or IX activity
40-49%

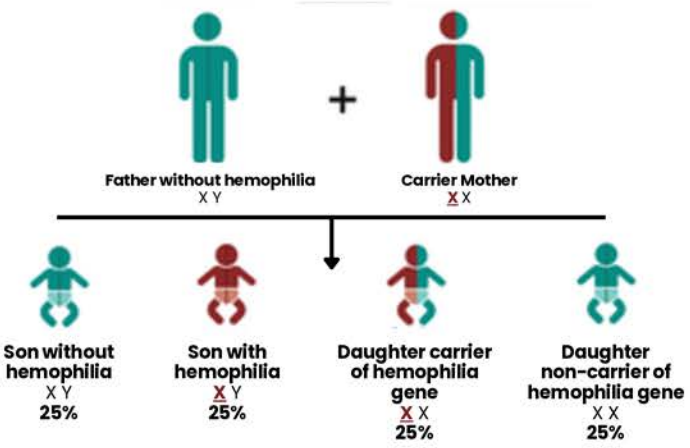
Mild
Factor VIII or IX activity
5%-40%

Moderate
Factor VIII or IX activity
1%-5%

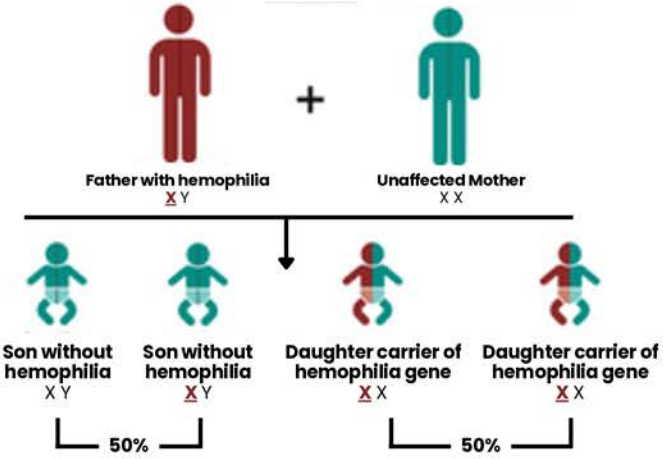
Severe
Factor VIII or IX activity
<1%

INHERITANCE
patterns in hemophilia

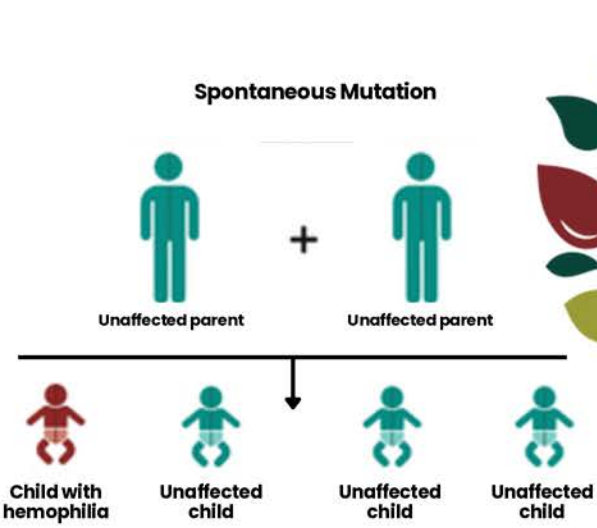
X-Linked Inheritance of Hemophilia: Carrier Mother and Father Without Hemophilia



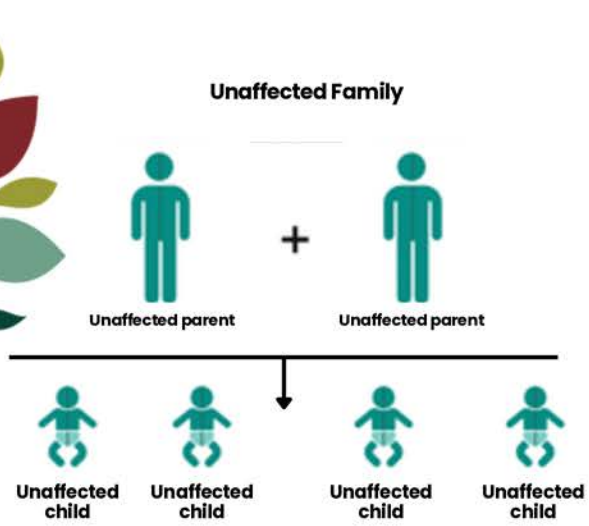
X-Linked Inheritance of Hemophilia: Father With Hemophilia and Mother Who Is Not A Carrier



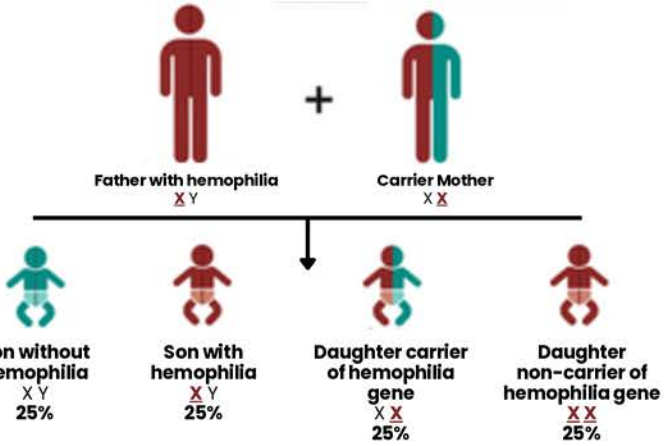
Spontaneous Mutation



Unaffected Family



X-Linked Inheritance of Hemophilia: Carrier Mother and Father With Hemophilia



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What is Platelet Deficiency?

Living with a platelet deficiency can be challenging, as platelets are the unsung heroes of our bloodstream, responsible for the crucial task of clotting. These small cells play a significant role in preventing excessive bleeding when we are injured. However, when platelet functions fail, it can lead to an increased susceptibility to bleeding. At HOC, we understand the unique struggles faced by individuals with platelet deficiencies, and our comprehensive care is tailored to provide the support and guidance needed to manage and improve your condition.

Definition

Platelets are small, disk-shaped cells made in the bone marrow that help blood clot. If platelets don't function properly, it can lead to increased bleeding.

Types

- **Quantitative Disorder** – A low platelet count, caused by the body not producing enough platelets or removing them too quickly.

- **Qualitative Disorder** – Platelets are produced in normal amounts, but are structurally or functionally defective, often due to missing or abnormal proteins or issues with platelet granules (storage pool disorder).

Genetic Inheritance

Platelet deficiencies can be inherited or occur without a family history. Diagnosing these disorders can be complex.

Symptoms

Symptoms include easy bruising, nosebleeds, gum bleeding, heavy menstrual bleeding, and bleeding after dental work or surgery.

What is Hereditary Hemorrhagic Telangiectasia? (HHT)

Hereditary Hemorrhagic Telangiectasia (HHT) is a condition characterized by the improper development of some blood vessels. It can lead to recurrent nosebleeds, digestive tract bleeding, and other related issues. Hemophilia Outreach Center is dedicated to providing support and resources for individuals and families affected by HHT. Through our services, you can discover valuable information about managing HHT, access expert guidance, and connect with a community of individuals who share similar challenges.

Definition

HHT is a disorder in which some blood vessels are not properly developed. A person with HHT can have malformed blood vessels, specifically blood vessels that lack capillaries. Capillaries are tiny blood vessels that connect arteries to veins.

Symptoms

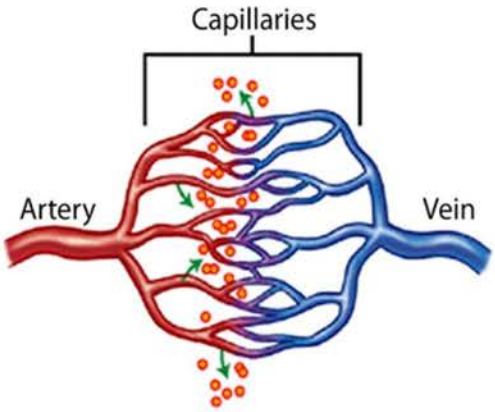
Without capillaries—the tiny vessels connecting arteries to veins—arteries attach directly to veins, increasing pressure and causing bleeding. HHT, also called Osler-Weber-Rendu (OWR), is named after doctors who studied it in the 1800s.

The most common symptom of HHT is nosebleeds, affecting about 90% of patients. They can be mild and infrequent or happen multiple times a day.

How Common

HHT affects approximately 1 in 5000 people

Normal Capillary Bed



Abnormal Capillary Bed from HHT

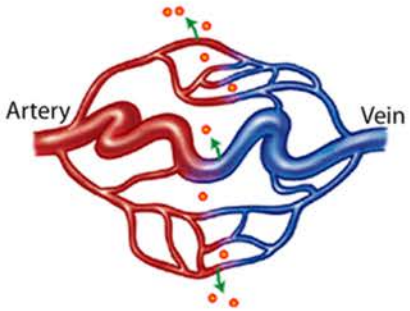


Image credit: CureHHT

What is Glanzmann's Thrombasthenia?

Glanzmann's Thrombasthenia (GT) is a rare, inherited bleeding disorder characterized by a deficiency of the glycoprotein IIb/IIIa complex, crucial for platelet aggregation and blood clotting. Patients with GT experience various bleeding symptoms, ranging from mild bruising to severe bleeding episodes. At Hemophilia Outreach Center, we are dedicated to empowering individuals with GT and their families through comprehensive care and support. Our services include personalized treatment plans, access to advanced therapies, and educational resources to navigate this challenging condition.

Definition

Glanzmann's Thrombasthenia (GT) is a genetic bleeding disorder caused by a malfunction in the platelets, which are essential for blood clotting. This condition results from a deficiency or dysfunction of the glycoprotein IIb/IIIa complex on the platelet surface. GT is characterized by prolonged bleeding times, even with minor injuries, due to the platelets' inability to form proper clots.

Symptoms

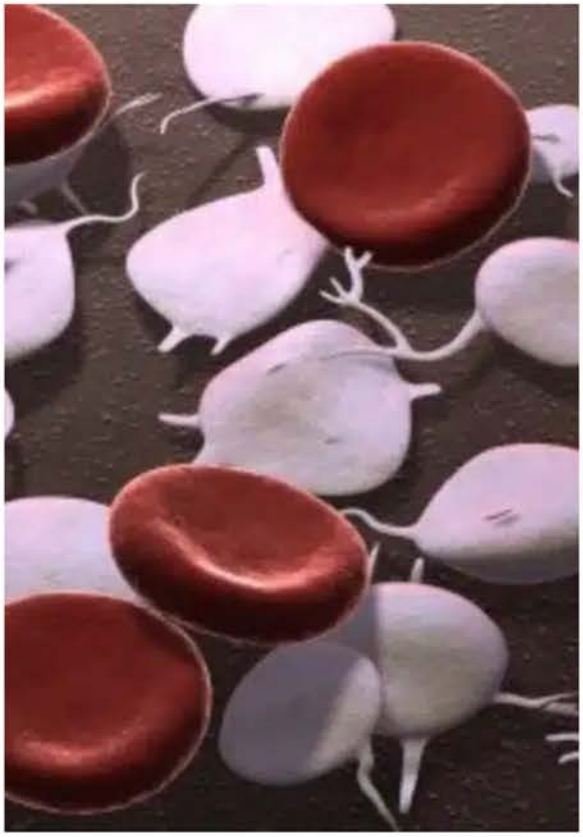
Common symptoms include easy bruising, frequent nosebleeds, bleeding gums, and, in severe cases, internal bleeding.

Diagnosis

GT is diagnosed through specialized blood tests that assess platelet function and genetic testing.

Management

Management of GT involves preventive care, treatment of bleeding episodes with platelet transfusions or other agents, and sometimes the use of antifibrinolytic drugs to reduce bleeding risk.



Other Rare Bleeding Disorders

Hemophilia Outreach Center is your partner in diagnosing and managing rare bleeding disorders like Factor 7 deficiency, Acquired Hemophilia, and Acquired von Willebrand's disease. We focus on positive outcomes and improving your quality of life through treatment, bleeding risk support, genetic counseling, and community connection.

What other bleeding disorders do we treat?

FACTOR 7 DEFICIENCY

Factor 7 deficiency is a rare genetic disorder caused by low levels or reduced activity of clotting factor 7, affecting about 1 in 300,000 to 500,000 people. It's inherited in an autosomal recessive pattern, requiring both parents to carry the gene. It affects men and women equally.

People with factor 7 deficiency are at risk for bleeding after trauma, surgery, or dental work, and may experience spontaneous joint or internal bleeding. Severity increases with lower factor levels. Women may have heavy menstrual bleeding and increased bleeding after childbirth.

ACQUIRED HEMOPHILIA

Acquired hemophilia is an autoimmune disease where antibodies destroy clotting factor 8, causing excessive bleeding. It affects men and women equally and may be triggered by autoimmune diseases, cancer, pregnancy, or medications, but often has no known cause. It's extremely rare, affecting about 1 in 1,000,000 people.

ACQUIRED VON WILLEBRAND'S DISEASE

The immune system can also attack von Willebrand factor, causing acquired von Willebrand's disease and bleeding issues.

UNSPECIFIED BLEEDING DISORDER

Unspecified bleeding disorders cause prolonged or excessive bleeding without a clear diagnosis. Symptoms include post-surgical or dental bleeding, bruising from minor trauma, nosebleeds, and heavy periods. The cause and inheritance are unknown.

Treatment may be needed before procedures, even without a diagnosis. Discuss any bleeding history with your care team and involve HOC.

MY NOTES

Print this page for your child!

Activity

Help Ivy find the words in the list below.

Circle all the words you can find in the puzzle.

Word List:

- ☐ VONWILLEBRAND
- ☐ HEMOPHILIA
- ☐ FACTOR
- ☐ PLATELETS
- ☐ GENETICS
- ☐ CLOTTING
- ☐ FIBRIN
- ☐ SUPPORT
- ☐ ADVOCATE
- ☐ INFUSION
- ☐ TREATMENT
- ☐ COMMUNITY
- ☐ AWARENESS

R I C A G Y N J I Z E V V J F O E F J P
A V Y U R L O B S D W I Q G I T M U W L
V W I Q D C O M M U N I T Y B B E T X A
O X A T C M F X M T P A H X R Y O Z G T
Y I N R T V G L X F P P M V I U C Y K E
W N Y E E Q N W R A O J O K N Z X F T L
C F C A R N N J F C O O E R I X Y I B E
O U L T R U E D T T X W P C T H K A M T
H S O M C M J S G O N C M I V N H I P S
V I T E Z A H J S R H E M O P H I L I A
T O T N G X A X W T N T G U F B Y F T S
A N I T X E E D R L J Q P A Q C A K I X
I Q N J J C N B V L B J M K F F S W F J
A W G Y I I T E X O F O T V R T D R X C
U Q C X L Z A Y T H C V F X T S J A J Y
Z L F A B P R L P I S A X V C Z T Q H Y
L Y F P D L Z R O Q C R T T T S F N I F
C Z J E J L D D C K H S S E A P S O Y O
B R G U E V Q N H U W R A A D U V Y Y J
V O N W I L L E B R A N D A I X D G Y Q

Hint: Search across, down, and diagonal!

The answer key to this puzzle is on the next page.

Activity

Help Ivy find the words in the list below. Answer Key

Circle all the words you can find in the puzzle.

Word List:

- ☑ VON WILLEBRAND
- ☑ HEMOPHILIA
- ☑ FACTOR
- ☑ PLATELETS
- ☑ GENETICS
- ☑ CLOTTING
- ☑ FIBRIN
- ☑ SUPPORT
- ☑ ADVOCATE
- ☑ INFUSION
- ☑ TREATMENT
- ☑ COMMUNITY
- ☑ AWARENESS

R	I	C	A	G	Y	N	J	I	Z	E	V	V	J	F	O	E	F	J	P
A	V	Y	U	R	L	O	B	S	D	W	I	Q	G	I	T	M	U	W	L
V	W	I	Q	D	C	O	M	M	U	N	I	T	Y	B	B	E	T	X	A
O	X	A	T	C	M	F	X	M	T	P	A	H	X	R	Y	O	Z	G	T
Y	I	N	R	T	V	G	L	X	F	P	P	M	V	I	U	C	Y	K	E
W	N	Y	E	E	Q	N	W	R	A	O	J	O	K	N	Z	X	F	T	L
C	F	C	A	R	N	N	J	F	C	O	O	E	R	I	X	Y	I	B	E
O	U	L	T	R	U	E	D	T	T	X	W	P	C	T	H	K	A	M	T
H	S	O	M	C	M	J	S	G	O	N	C	M	I	V	N	H	I	P	S
V	I	T	E	Z	A	H	J	S	R	H	E	M	O	P	H	I	L	I	A
T	O	T	N	G	X	A	X	W	T	N	T	G	U	F	B	Y	F	T	S
A	N	I	T	X	E	E	D	R	L	J	Q	P	A	Q	C	A	K	I	X
I	Q	N	J	J	C	N	B	V	L	B	J	M	K	F	F	S	W	F	J
A	W	G	Y	I	I	T	E	X	O	F	O	T	V	R	T	D	R	X	C
U	Q	C	X	L	Z	A	Y	T	H	C	V	F	X	T	S	J	A	J	Y
Z	L	F	A	B	P	R	L	P	I	S	A	X	V	C	Z	T	Q	H	Y
L	Y	F	P	D	L	Z	R	O	Q	C	R	T	T	T	S	F	N	I	F
C	Z	J	E	J	L	D	D	C	K	H	S	S	E	A	P	S	O	Y	O
B	R	G	U	E	V	Q	N	H	U	W	R	A	A	D	U	V	Y	Y	J
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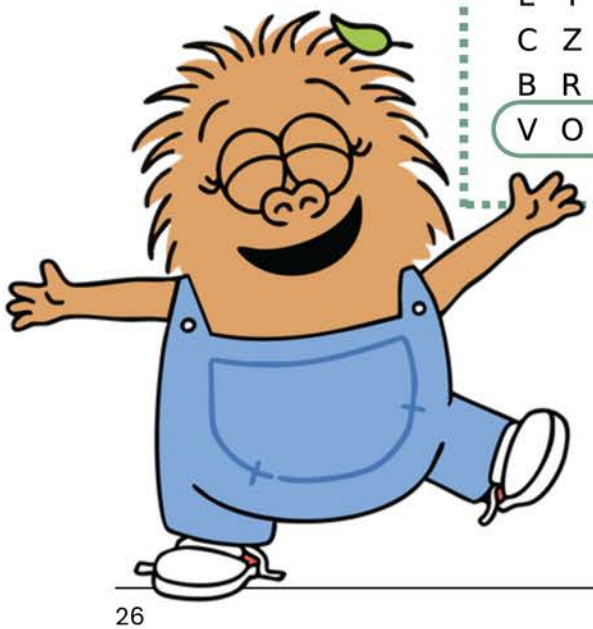


Section 03

Notifying Others

The Importance of Notifying Others

Managing a bleeding disorder means making sure everyone involved in your child's care is informed and prepared. This section outlines key steps for notifying healthcare providers, teachers, and caregivers, and provides essential resources for handling emergencies. Taking these proactive measures ensures that those around your child know how to respond quickly and appropriately in any situation.

1 We strongly suggest obtaining these FREE items from HOC:

Medical ID bracelets & dog tags

Seatbelt straps

ER ID Cards

2 In the event of an emergency:

Please add your child's medical history and emergency contact information to your phone and your child's cell phone.

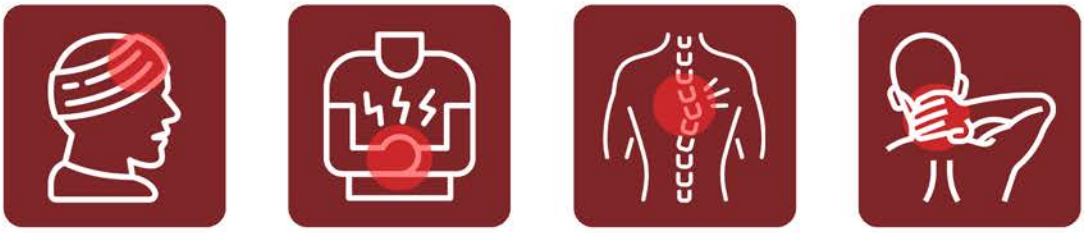
3 Notify your pediatrician, other providers, & people about your child's bleeding disorder

Not all healthcare providers specialize in bleeding disorders, HOC can collaborate and share information with them!

4 Evaluations

- **24/7 Care**
  - Your **HOC nurses are available 24 hours a day and 7 days a week** to help you assess and navigate your child being seen at the clinic or ER.

- **Life Threatening bleeds**
  - **ANY** injury involving the head, abdomen, spine, or neck



- **Questions to ask when determining a bleed**
  - Is the area swollen, red, bruised, or warm to the touch?
  - Is your child's mobility affected?
  - Does your child say the area feels tingly or bubbly?
    - **See "Is This More Than Just A Bruise?" handout** here:
      - **https://qrco.de/bfxTIF**
    - Call to talk it out with your HOC nurses!

- **RICE**
  - Any injury

Rest
Avoid use if possible

Ice
Use a barrier between skin and ice
20 minutes on/20 minutes off

Compression
Not so tight there is numbness, tingling or discoloration below wrap

Elevation
Above your heart is best

- **How to Manage a Nose Bleed**
  - Nosebleeds aren't always visible. Blood can go down the back of throat. May cause nausea.
  - **WATCH VIDEO:**
    https://youtu.be/wLVcc_EhFA0

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Managing A Nose Bleed

- Apply pressure to the nose
- Tilt head forward, not backwards, so blood does not go down the back of the throat
- Apply an ice pack while continuing to apply pressure
- Nampon: Expands for gentle pressure inside the nose

1

Apply Pressure

2

Tilt Head Forward

3

Ice Pack

4

Nampon

Ask an HOC nurse about the many ways to prevent a nosebleed.

DIY Gel freezer pack recipe:

Ingredients

- 2 cups - Water
- 1 cup - Rubbing Alcohol
- 2 - 1 quart Freezer Bag

Directions

1. Mix water and rubbing alcohol.
2. Double up the quart size freezer bag.
3. Pour mixture into bag and place in freezer.
   - This will make a "slushy" moldable ice pack.
   - Ice pack can be refrozen and reused.

5 Iron Deficiency Anemia

- This can occur following multiple nose bleeds, frequent heavy periods, or with some GI bleeds. **CALL YOUR HOC NURSES 24/7** with any of these symptoms:

Fatigue

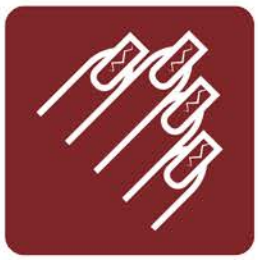
Unusual cravings and smells

Chewing on ice

Restless legs

Pale Skin

Fast heartbeat



Brittle nails

6 Musculoskeletal complications

- Untreated or postponed treatment for joint bleeds >2 hours from onset of symptoms can cause long term damage to the joint. **CALL YOUR HOC NURSES 24/7!**

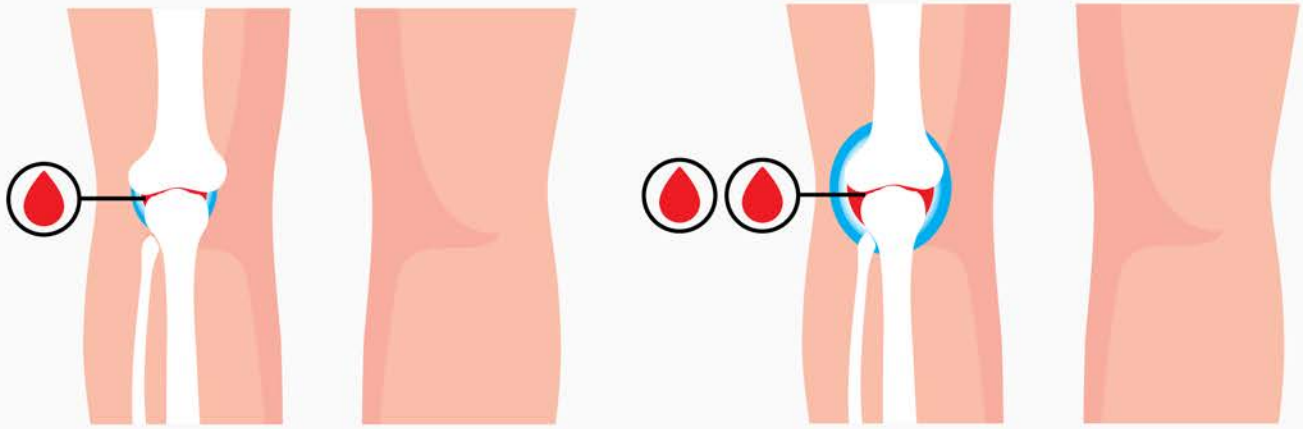
Visit **hemophiliaoutreach.org/educational-resources-new/** to download educational resources

What Happens in a Joint Bleed?

Early Onset

Treatment is ideal in this stage; least amount of joint damage and typically able to resume activities almost immediately.

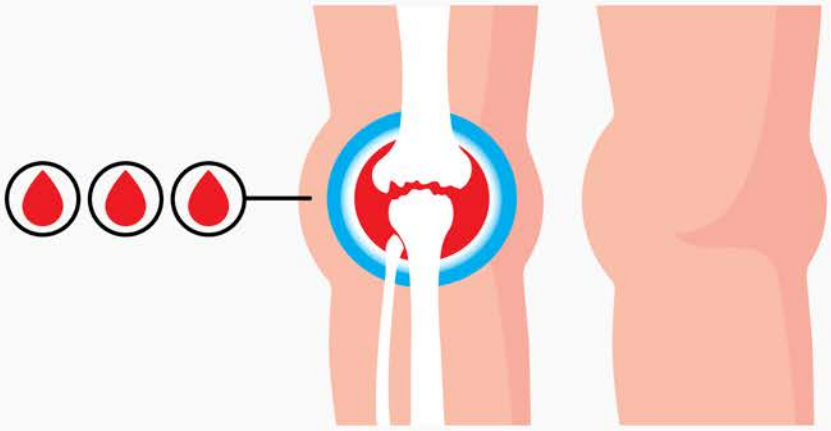
Condition: Tingling, Mild discomfort, may or may not have limited range of motion.



Advanced

Additional dosage of treatment needed. May advance joint disease and leave you feeling weak for a longer period of time.

Condition: heat, severe pain, swelling, decreased range of motion.



7 Medications and supplements to avoid

This list is not all inclusive. It is important for your HTC to ask what medications and supplements patients are on when they come in for their annual exam.

- Alka Seltzer*
- Aspirin
- NSAIDS
- Pepto Bismol
- Excedrin
- Percodan
- Fish Oil*
- Omega 3
- Ginseng
- St. John's Wort
- Vitamin C
- Vitamin E
- Garlic*
- Ginger*
- Licorice*

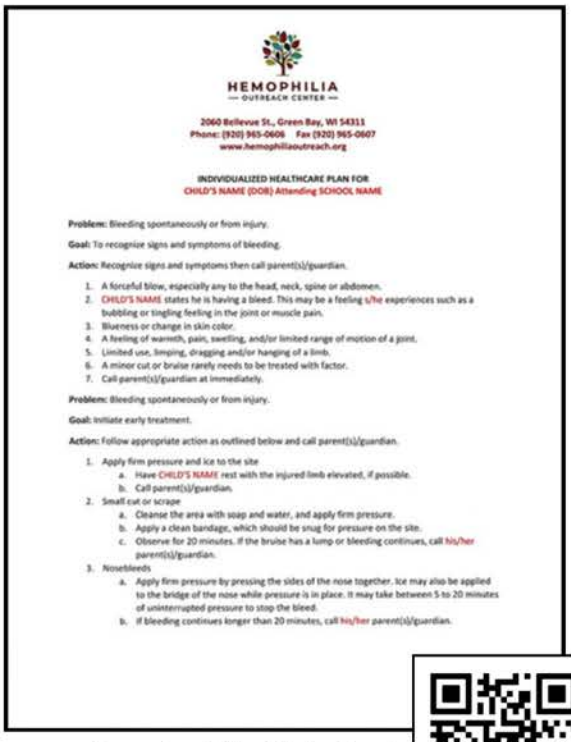
**Safe to eat and drink as food*

8 Information and staff to help you and your child:

- **Home**
  - Begin keeping a detailed journal, regardless of your child's age. This practice helps both you and your child recognize patterns and distinguish between a bleed and an injury ("owie"). **CALL YOUR HOC NURSES 24/7!**
    - Record important details such as whether the injury occurred on a prophylaxis (prophy) day or a non-prophy day and note if similar activities have led to bleeds in the past.
    - Over time, the journal becomes a valuable tool for building confidence and empowering your child to take an active role in understanding and managing their condition.

- **School**
  - Play it Safe handout for choosing activities and sports for your child
  - Individualized Health Plans for your child's teachers and school nurse
  - In-service education for your child's school staff and/or classroom

Download "Playing It Safe" poster here:
https://qrco.de/bfxTSF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2060 Bellevue St., Green Bay, WI 54311
Phone: (920) 965-0606 Fax (920) 965-0607
www.hemophiliaoutreach.org

INDIVIDUALIZED HEALTHCARE PLAN FOR
CHILD'S NAME (DOB) Attending SCHOOL NAME

Problem: Bleeding spontaneously or from injury.

Goal: To recognize signs and symptoms of bleeding.

Action: Recognize signs and symptoms then call parent(s)/guardian.

1. A forceful blow, especially any to the head, neck, spine or abdomen.
2. CHILD'S NAME states he is having a bleed. This may be a feeling s/he experiences such as a bubbling or tingling feeling in the joint or muscle pain.
3. Blueness or change in skin color.
4. A feeling of warmth, pain, swelling, and/or limited range of motion of a joint.
5. Limited use, limping, dragging and/or hanging of a limb.
6. A minor cut or bruise rarely needs to be treated with factor.
7. Call parent(s)/guardian at immediately.

Problem: Bleeding spontaneously or from injury.

Goal: Initiate early treatment.

Action: Follow appropriate action as outlined below and call parent(s)/guardian.

1. Apply firm pressure and ice to the site
   a. Have CHILD'S NAME rest with the injured limb elevated, if possible.
   b. Call parent(s)/guardian.
2. Small cut or scrape
   a. Cleanse the area with soap and water, and apply firm pressure.
   b. Apply a clean bandage, which should be snug for pressure on the site.
   c. Observe for 20 minutes. If the bruise has a lump or bleeding continues, call his/her parent(s)/guardian.
3. Nosebleeds
   a. Apply firm pressure by pressing the sides of the nose together. Ice may also be applied to the bridge of the nose while pressure is in place. It may take between 5 to 20 minutes of uninterrupted pressure to stop the bleed.
   b. If bleeding continues longer than 20 minutes, call his/her parent(s)/guardian.

Download "Individualized Healthcare Plan" here:
https://qrco.de/bfxTXY

Coordination of Care

HOC will provide orders and/or recommendations for treatment surrounding surgical procedures and any postoperative doses that may be needed. This is very important because most primary care physicians and/or general surgeons do not know what treatment is needed for a bleeding disorder.

STEP-BY-STEP

1
HOC is notified by the patient or physician's/ surgeon's office

2
Procedure details are verified with physician's/ surgeon's office

3
Orders are obtained from HOC's hematologists

4
Orders are faxed to physician's/ surgeon's offices and any ancillary departments (i.e. surgery center, pharmacy, etc.)

5
If patient will be receiving clotting factor medication at the hospital, HOC verifies with pharmacy that they can provide the medication. If unable to, HOC has the ability to provide hospital with clotting factor medication

6
HOC then walks through a plan of care with the patient to ensure that the patient fully understands the plan of care

7
HOC will verify that all the orders are set several days before the procedure

8
The day after the procedure, HOC staff will follow up with the patient and/or hospital staff to ensure there are no bleeding complications. Physician's/Surgeon's office is made aware that they should call HOC staff if there are any complications during the procedure. They are informed that HOC staff are on call 24/7

Notify HOC of Upcoming Procedures

Major procedures, including but not limited to:

- Joint replacement
- Hysterectomy
- Arthroscopic surgeries
- Abdominal surgeries
- Brain surgery
- Neck and/or spinal surgeries

Dental procedures, including but not limited to:

- Impacted teeth removal
- Wisdom teeth removal
- Improve fit of dentures
- Dental implants
- Unequal jaw growth
- Cleft lip and cleft palate repair
- Facial infections
- Facial injury repair
- Gum graft
- Tooth implants
- Maxillofacial surgery
- Root canal
- Jaw and teeth repair following an injury
- Other procedures that require local anesthetic
- **Prophylactic Antibiotic dose for those with ports**

Minor procedures, including but not limited to:

- Vaccinations
- Colonoscopy
- Tattoo/tattoo removal
- Esophagogastroduodenoscopy (EGD)
- Skin lesion removal
- Cataract surgery
- Circumcision
- Breast Biopsy
- Laparoscopic procedures
- Burn excision and debridement procedures
- Excision of skin cancers
- Skin biopsy
- Excision of cyst
- Ingrown toe nails
- Trigger finger
- Carpal tunnel
- Sclerotherapy to eliminate spider veins on the legs
- Incision and drainage of abscesses
- Stitches and/or staples

Download:

VACCINATIONS INFO AND CARE SHEET

qrco.de/bfqOYV

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WHEN IN DOUBT, CALL HOC

Green Bay: (920) 965-0606

Wausau: (715) 680-9810

NOTE: This list is not all inclusive

MY NOTES

Section 04

Understanding Your Care Team

Know Your Comprehensive Care Team

Building a strong relationship with your HOC care team is essential for managing your child's bleeding disorder. Your team includes nurses, social workers, physical therapists, and other specialists who work together to provide personalized care and support. Understanding their roles and how they can help ensures you have the right guidance to navigate treatments, emergencies, and everyday care with confidence.

Your Hematology Providers

- Educates you about your bleeding disorder.
- Answers questions about your bleeding disorder.
- Determines your treatment plan (medication) to manage your bleeding disorder.
- **GOAL:** Continuously monitors your bleeding disorder so you can live a healthy, happy life!

Your Primary Care Provider

- Knows your health history and goals.
- Provides regular health screenings, which reduces emergency room visits.
- Answers any questions you have about your general health.
- Helps you when you're not feeling well.
- **GOAL:** Your primary care provider is the person you contact for all your healthcare needs which aims to improve patient health outcomes.

Your Medical Team

- Educates you about your bleeding disorder.
- Teaches you about your bleeding disorder medication.
- Teaches other people in your life about your bleeding disorder.
- Gives you your medication when needed.
- Helps you when you're hurt and have a bleed.
- **GOAL:** Helps you learn about your bleeding disorder and treats your bleeding disorder so you can live a healthy, happy life!

Your Behavioral Health Specialist

- Helps you work through any feelings you may have about your bleeding disorder.
- Helps you navigate any challenging times in your life.
- Teaches you different ways to cope with your feelings.
- **GOAL:** Keeps your mind and thoughts healthy, so you can live a happy, healthy life!

Your Physical Therapists

- Gives you exercises to keep your joints healthy and moving properly.
- If you have a bleed in your joint, they help you to exercise to maintain your range of motion.
- Encourages exercise and proactive care to keep you moving through every stage of life.
- **GOAL:** Educates you about the importance of exercise so your joints and muscles stay healthy!

Your Dental Hygienist

- Dental Assessments (looks at your teeth and gums).
- Educates you about the importance of oral hygiene.
- Gives you information about your bleeding disorder to share with your dentist.
- Helps you to find a dentist if you don't have one.
- **GOAL:** Helps you to achieve the best oral health possible to reduce the chances of oral bleeds.

Your Nutritionist

- Helps you to establish healthy eating habits.
- Educates you about different foods and how they impact your health.
- Helps you with food changes in order to be healthier (example try cauliflower rice instead of regular rice).
- **GOAL:** Helps you to achieve a well-balanced diet so you can be the healthiest version of yourself.

Your Genetic Counselor

- Goes through your family history with you to determine who was the first person in your family to have a bleeding disorder.
- Educates you about how you inherited your bleeding disorder.
- **GOAL:** Helps you to understand how bleeding disorders are passed from generation to generation of family members.

Your Social Worker

- Conducts assessments for pediatric and adult patients to understand unique situations and identify areas for additional support.
- **GOAL:** Ensures individuals have access to necessary resources and assistance to thrive.

Your Insurance Navigators

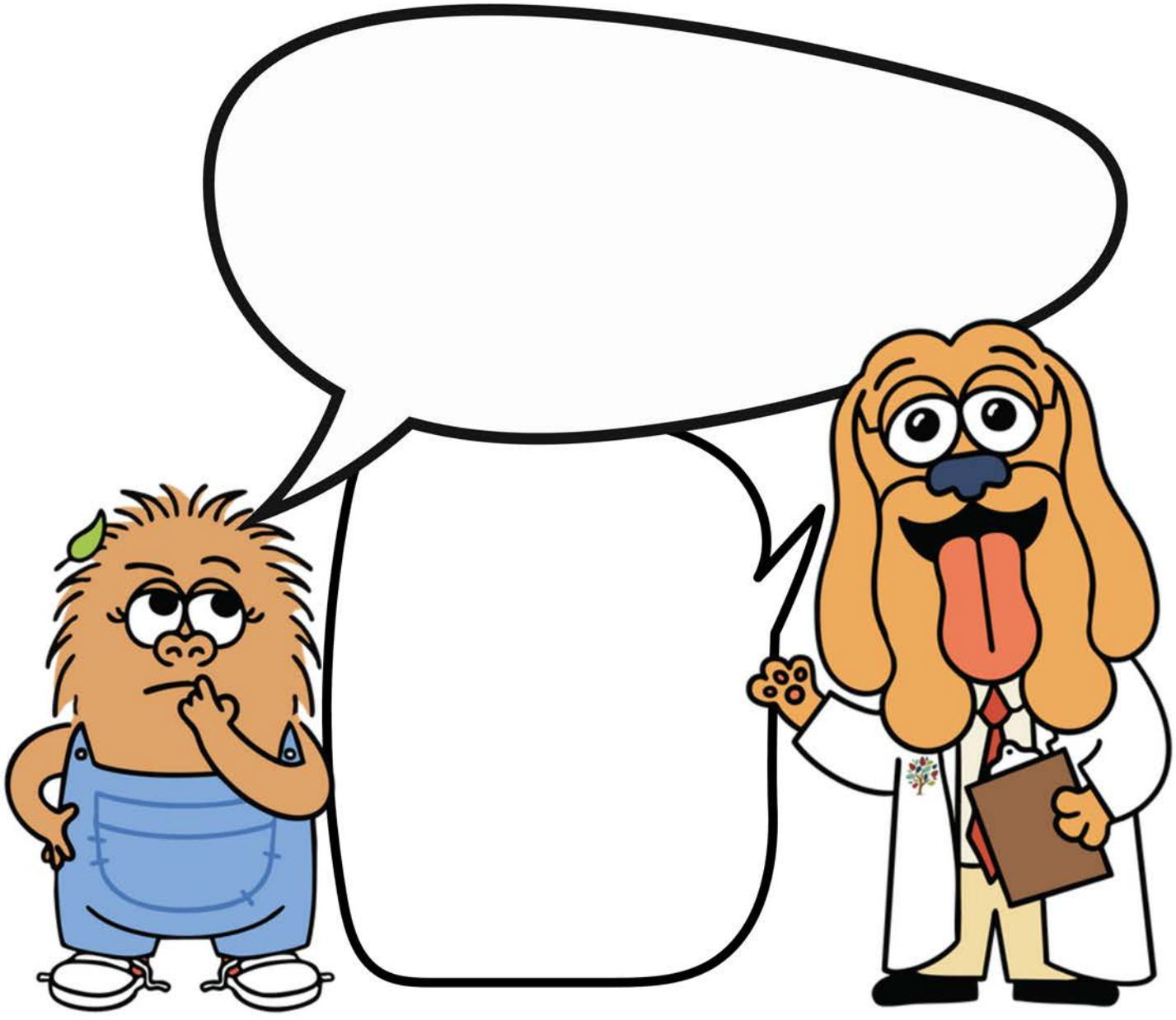
- Works with insurance companies to ensure that you are able to get your bleeding disorder medication.
- Educates you about the financial assistance options that are available, should you ever need them.
- **GOAL:** Helps you to navigate insurance changes and barriers.

Print this page for your child!

Activity

Ivy knows that it's important to talk to your doctor.

In the bubble at the top, write a question that you would like to ask your doctor, and in the bubble at the bottom, ask your parent or guardian to write in your doctor's answer.



Section 05

How to help your child grow with their bleeding disorder

How to help your child grow with their bleeding disorder

Empowering a child with a bleeding disorder starts with fostering curiosity, confidence, and independence. Through open conversations, creative learning, and everyday experiences, they can develop a deeper understanding of their condition in a way that feels natural and engaging. Encouraging questions, using relatable analogies, and providing emotional support helps them build the skills they need to manage their health with confidence. By nurturing their ability to communicate and take an active role in their care, you're laying the foundation for lifelong self-advocacy and resilience.

Educating leads to empowering your child

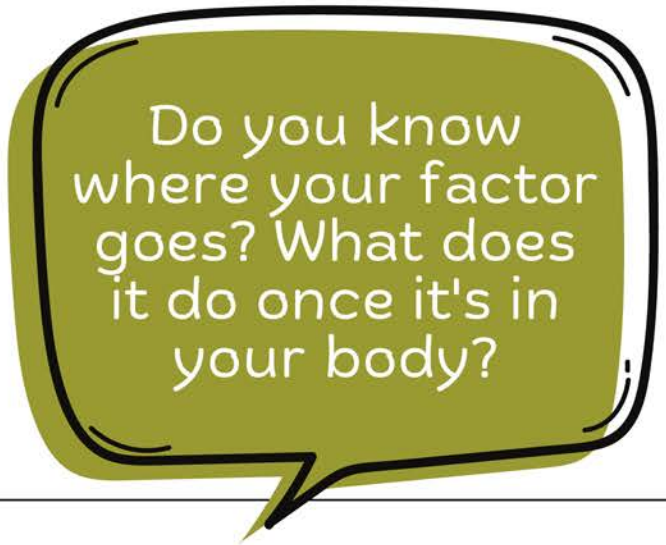
- Your child may communicate well using art or stuffed animals.
- Take the time to truly listen to your child without rushing, offering advice, or preaching. Active listening allows you to uncover any misconceptions or gaps in their understanding. By encouraging them to elaborate, you can gain deeper insights and clarify misunderstandings effectively. Ask open-ended questions like, **"What do you mean by that?"** or **"Can you draw me a picture?"** and confirm your understanding with phrases like, **"Let me see if I understand you correctly."**
- **Consider Making a "POKE" PLAN:** Please see this site for additional info and preparation for visits: www.megfoundationforpain.org

Celebrate their efforts with positive reinforcement, such as, **"Good answer!"** or **"You really know a lot, don't you?"** even if their response isn't entirely correct. This approach helps you understand how your child processes information—whether they think step by step, magically, concretely, or abstractly—so you can tailor your responses to better meet their needs.

- Seek emotional support and coping advice from other adults, such as trusted friends, family members, or professional counselors. Avoid placing the burden of your feelings—such as guilt, sadness, or despair—on your child. Preserving their emotional well-being allows them to focus on their own growth and understanding without feeling overwhelmed by adult concerns.

- Hold up a leaf and point out the veins to your preschooler. Ask, "What do you think these veins do?" Then explain that the veins carry food and water to the leaf, keeping it healthy and green. If you're using an oak leaf, note how it resembles a hand. Encourage your child to hold up their hand and compare it to the leaf. Show them their veins and ask, **"What do you think is inside your veins? What are they for?"** Use this opportunity to draw similarities between the leaf's veins and their own, helping them understand that factor travels through their veins to keep them healthy, just like the leaf.

- School-age children on prophylaxis often understand that factor helps prevent injuries and provides protection, but they may not fully grasp how it works. After an infusion, ask your child, **"Do you know where your factor goes? What does it do once it's in your body?"** Explain that factor gradually breaks down in the body over 8 to 12 hours. You can compare this process to eating meals three times a day—just as food breaks down and fuels our bodies, the factor works to keep their blood healthy but is eventually used up. This analogy can help your child better understand how prophylaxis helps maintain their factor levels and keeps them protected.



HEMOPHILIA
— OUTREACH CENTER —

Hemophilia Treatment Center #564

Transition Policy

Our Goal

HOC is committed to preparing young people with a bleeding disorder diagnosis to transition from **pediatric care (where caregivers make most decisions)**, to **adult care (where patients will take full responsibility for the decision-making process and manage their own bleeding disorder care).** Helping youth learn how to manage all aspects of their bleeding disorder care is a process that is best achieved when patients, caregivers, and the medical team all work together.

What is "transition"?

Transition is a planned process to further educate young adults about their bleeding disorder diagnosis, medical information, skills to best manage their diagnosis, and individualized plan of care. The goal of transition is so that when patients become adults, they can independently manage their bleeding disorder diagnosis with confidence.

What to expect during the transition process

- Transition Education is a partnership between the patient, caregivers, and the Hemophilia Treatment Center (HTC). Everyone involved will assist in creating an environment for success.
- Transition Education is broken down into stages, as opposed to age groups, to accommodate the idea that patients will chart their own path and timeline at a comfortable pace.
- Together, we will set educational goals at each appointment to work through each stage of transition.

Meet your Adult Providers

Different ages present different bleeding complications and concerns. Between ages 18-22 years old, your bleeding disorder care will be transitioned from the Pediatric Provider (Dr. Freeman or Dr. Friedman) to the Adult Providers (Dr. Ryan or Andrea Buxton, APNP)

Dr. Matthew Ryan

Andrea Buxton, APNP

Privacy & Confidentiality

By law, you are an adult at the age of 18, we will only discuss your health information with you. While some adults choose to involve their parents/caregivers or others in their healthcare choices, who you choose to include in those decisions is entirely your choice.

Stages of Transition Goals

Stage 1

- **Know the name of your bleeding disorder**
- **Know the name of your bleeding disorder medication(s)**
- **Understand how to identify a bleed**
- **Know the name of your treatment center**
- **Understand self-infusions** (for prophy patients, does not need to self-infuse, just understand the process. Self-infusion is a bonus)
- **Know what RICE stands for and how it is applied**
- **Understand the long-term goal of the transition process**

Stage 2

- **Know your bleeding disorder medication dose**
- **Carry your ER card/medical ID bracelet/have your med alert on your phone**
- **Know your HTC team members**
- **Know how and when to order your bleeding disorder medication**

Stage 3

- **Know where your bleeding disorder medication is and how to check expiration dates**
- **Understand bleeding logs** (Robust Health)
- **Know how and when to call in bleeding disorder medication orders and coordinate pick up**
- **Understands the importance of attending scheduled appointments**
- **Understands how health insurance is obtained** (employer, marketplace, state insurance, etc.)

Stage 4

- **Consistently call in own bleeding disorder medication orders**
- **Know insurance and carry card as necessary**
  - **Plans for insurance** (age 25, f/u age 25.5)
  - **age 18 for Medicaid patients**
- **Know when to call your HTC (including on-call service)**
- **Consistently respond to inquiries from your HTC and show up for appointments**
- **Understand your bleeding disorder and how it affects your body**
- **Has MyChart access (optional)**

Encourage your child's help to foster independence

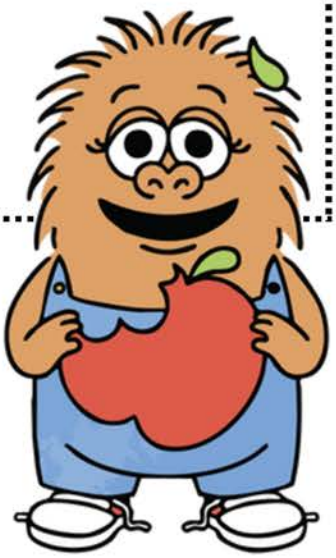
Print this page for your child!

Activity

Setting Goals

When Ivy is at school or at home, she needs to always be prepared, and that includes setting goals. In the space below, write down some of your goals.

Now, circle the goal that is most important to you. List the steps that you are going to take to achieve this goal. Be sure to write down any help you may need to achieve this goal.



Steps to achieve my goal

Activity

Infusion Steps - Word Match

Help Ivy match each definition to the right number that shows the steps in the infusion process.

_____ **Step 1**

_____ **Step 2**

_____ **Step 3**

_____ **Step 4**

_____ **Step 5**

_____ **Step 6**

_____ **Step 7**

_____ **Step 8**

_____ **Step 9**

_____ **Step 10**

_____ **Step 11**

_____ **Step 12**

_____ **Step 13**

A – Snuggly place tourniquet above site chosen for infusion

B – Apply band-aid if desired

C – Release the tourniquet

D – Screw the second syringe on, and pull back so there is not any air in the line

E – Clean the vein with an alcohol wipe, and let the alcohol dry

F – Slowly push the factor. If swelling or burning occurs, select a new area.

G – Slowly push in the second syringe of factor. Do not push in the air at the end

H – Wash hands with soap & water

I – Once the first syringe is empty, pinch the tubing and take off the syringe

J – Take out the needle

K – Screw on the syringe, and gently pull back so a small amount of blood mixes with the factor

L – Place gauze on the infusion site, and hold pressure

M – Put the needle into the vein. Blood should begin to flow down the tubing if in the vein

Activity

Infusion Steps - Word Match - Answer Key

Help Ivy match each definition to the right number that shows the steps in the infusion process.

H ____ **Step 1**

A ____ **Step 2**

E ____ **Step 3**

M ____ **Step 4**

K ____ **Step 5**

C ____ **Step 6**

F ____ **Step 7**

I ____ **Step 8**

D ____ **Step 9**

G ____ **Step 10**

J ____ **Step 11**

L ____ **Step 12**

B ____ **Step 13**

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Section 06

Treatment Options

Treatment Options

Replacement factor therapy is the main treatment for Hemophilia and von Willebrand Disease (vWD). It involves replenishing the missing clotting factors in the blood. These clotting factor concentrates are either derived from treated human blood to minimize infection risk or created using genetically engineered cells. The latter, known as recombinant clotting factor, has become the most widely used treatment for both conditions.

Factor can be used on-demand or prophylactically. **On-demand therapy** is administered only when a bleeding episode occurs, whereas **Prophylaxis, or replacement therapy,** is provided regularly to prevent bleeding episodes before they happen.

Factor Replacement Products:	These can be used prophylactically or on demand. • Factor VIII (eight) • Factor IX (nine) • Von Willebrand's
Non-Factor Products:	These can be used prophylactically. • A humanized monoclonal modified bispecific antibody that mimics Factor VIII. • An anti-tissue factor pathway inhibitor that allows thrombin generation and enhances coagulation.
DDAVP (Desmopressin Acetate):	A synthetic form of vasopressin that helps the body regulate both water balance and blood flow. It releases the stored von Willebrand's factor into the blood stream. This is used by vWD patients and mild Hemophilia patients who have been tested and are responsive to this treatment.
Amicar Solution:	An oral solution that prevents blood clots from breaking down. This is most often used for dental/mouth bleeds and nose bleeds.
Lysteda Tablets:	A man-made protein that helps prevent the breakdown of clots. This is used most often to help lighten heavy periods.
Tranexamic Acid Solution:	A man-made protein that helps prevent the breakdown of clots. This is used most often with nose bleeds.
Gene Therapy:	It utilizes a modified virus, known as a vector, to transport a functional copy of the Factor VIII OR Factor IX gene into liver cells, allowing the body to generate clotting factor independently. This is a once in a lifetime infusion for Hemophilia A and Hemophilia B patients.
Bypassing Agents	Used for Inhibitor & FVII patients

Activity

Bleeding Disorder Pre/Post Test

1 **Which of the following are bleeding disorders? Circle all that apply.**

a. Glanzmanns
b. Von Willebrand disease
c. Hereditary hemorrhagic telangiectasia
d. Hemophilia

2 **What are hemophilia and Von Willebrand disease?**

a. A digestive disorder
b. A type of cancer
c. A blood clotting disorder
d. A skin condition

3 **Which of the following is NOT a sign of a bleeding disorder?**

a. Bruising
b. Bloody nose
c. Constipation
d. Swollen joints

4 **What causes most bleeding disorders?**

a. Virus
b. Genetic mutation
c. Bacteria
d. The cause is unknown

5 **Only men can get hemophilia?**

a. True
b. False

6 **Women can only be carriers for hemophilia.**

a. True
b. False

7 **What is the main symptom of hemophilia and Von Willebrand disease??**

a. Bleeding
b. Headache
c. Fatigue
d. Muscle Pain

8 **Another name for hemophilia is Von Willebrand disease?**

a. True
b. False

9 **Is there a cure for hemophilia and Von Willebrand disease??**

a. Yes
b. No

10 **What is the life expectancy for someone with hemophilia?**

a. Same as someone without the disorder
b. Teens
c. Twenties
d. It varies

11 **Bleeding from a bleeding disorder only happens with injury or trauma.**

a. True
b. False

Activity

Bleeding Disorder Pre/Post Test - Answer Sheet

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Section 07

Building Strength Through Resilience

Nurturing Resilience in Your Child

Resilience is the ability to adapt, recover, and thrive in the face of challenges, stress, or adversity. Every child possesses the innate capacity for resilience, but it can be nurtured and strengthened with the right tools and support. By fostering open communication, teaching effective coping strategies, and encouraging understanding of their bleeding disorder, you can empower your child to face life's challenges with confidence. Building resilience within your family creates a strong foundation, enabling everyone to navigate difficulties together while fostering a sense of hope, strength, and connectedness.

Key Protective Factors for Building Resilience

Protective factors that encourage the development of resilience in children generally fall into the following categories:

1 Individual Characteristics

Positive Self Image

Confidence in one's abilities and a sense of self-worth.

Emotional Regulation

The ability to manage emotions effectively in various situations.

Problem-Solving Skills

Capacity to think critically and make constructive decisions.

Sense of Purpose

Having goals, aspirations, and a belief in a meaningful future.

Adaptability

Flexibility in adjusting to changes and challenges.

2 Family Environment

Supportive Relationships

A loving and stable relationship with parents, caregivers, or other family members.

Effective Communication

Open, honest, and age-appropriate discussions within the family.

Constant Routines

Predictability and structure that provide a sense of security.

Parental Resilience

Caregivers who model coping strategies and demonstrate their own resilience.

These protective factors work together to create a supportive ecosystem that fosters resilience, helping children face challenges with strength and adaptability.

3 Social Connections

Positive Peer Relationships

Friendships that offer support, encouragement, and a sense of belonging.

Mentors & Role Models

Trusted adults who offer support and encouragement. HOC provides mentor programs and camp opportunities to help kids build confidence and connection.

Community Engagement

Participation in school, religious, or community groups that foster social inclusion. Involvement with HOC!

MY NOTES

WHEN TO COMMUNICATE WITH

Checklist

Note: This list is not all inclusive

HEMOPHILIA
— OUTREACH CENTER —

Print this page for your child!

- **When having a _____**

  Hint: 

- **When you _____ you are having a bleed**

  Hint: 

- **When you are _____**

  Hint: 

- **When you have a _____ of insurance**

  Hint: 

- **When ordering your _____**

  Hint: 

- **When you have an upcoming _____ , _____ , or _____**

  Hint:   

- **When you have upcoming _____**

  Hint: 

- **When you need to make an HOC _____**

  Hint: 

WHEN TO COMMUNICATE WITH

Checklist

Note: This list is not all inclusive

HEMOPHILIA
— OUTREACH CENTER —

- **When having a** ___*bleed*___
  Hint: 
- **When you** ___*think*___ **you are having a bleed**
  Hint: 
- **When you are** ___*injured*___
  Hint: 
- **When you have a** ___*change*___ **of insurance**
  Hint: 

- **When ordering your** ___*medication*___
  Hint: 
- **When you have an upcoming** ___*procedure*___ **,** ___*surgery*___ **, or** ___*dental work*___
  Hint: 
- **When you have upcoming** ___*travel*___
  Hint: 
- **When you need to make an HOC** ___*appointment*___
  Hint: 

Section 08

Next Steps for Your Family

Next Steps for Your Family

The material in this manual is designed to guide and support you through the unique challenges of parenting a child with a bleeding disorder. It is up to you to decide how best to apply what you've learned in a way that fits the needs of your family. Every child and every family is different, so the solutions to the challenges you face will also vary.

What matters most is that you recognize you are not alone on this journey. Support is available, and by continuing to learn and adapt, you can provide your family with the best possible opportunities to thrive.

Take time to celebrate the successes—whether it's progress in your parenting approach, milestones achieved as a family, or your child's individual growth. Each success is a testament to your resilience, love, and commitment. Keep moving forward with confidence, knowing that every step you take is building a stronger foundation for your family's future.

Main Takeaways

- HOC Nurses available 24/7 in **Green Bay at 920-965-0606** and in **Wausau at 715-680-9810!**
- Call HOC Nurses **EVERY TIME head, neck, spine, or abdomen are injured!**
- Call HOC Nurses with **EVERY suspected bleed!**
- It's essential to maintain your connection with HOC, **even if your child doesn't currently require our services. Life is unpredictable—accidents can happen, dental procedures may arise, and surgeries might become necessary.**
- And remember ...

Additional Resources to gain knowledge in the bleeding disorder community.

- VWD Connect Foundation at https://vwdconnect.org
- Partners in Bleeding Disorders Education at https://partnersprn.org
- National Bleeding Disorders Foundation at https://www.bleeding.org
- From The American Academy of Pediatrics https://healthychildren.org
- American Thrombosis and Hemostasis Network at https://athn.org
- Hemophilia Alliance Foundation and Bleeding Disorders at https://hemoalliance.org
- The Bleeding Disorders Magazine at https://hemaware.org
- Great Lakes Hemophilia Foundation and Bleeding Disorders at https://glhf.org
- Camp Klotty Pine at https://glhf.org/what-we-do/camp
- Hemophilia Treatment Centers https://www.cdc.gov/hemophilia/treatment/treatment-centers.html
- Foundation for Women and Girls with Bleeding Disorders at https://www.fwgbd.org/clinics
- Hemophilia of Georgia at https://www.hog.org
- Hemophilia of Indiana at https://hoii.org

Conferences:

- Coalition for Hemophilia B
- VWD Connect has a conference specific to vWD
- NOW is a national education for bleeding disorders conference
- HHT has a conference specific to Hereditary Hemorrhagic Telangiectasia
- NBDF Annual meeting
- WI Bleeding Disorders

MY NOTES

Bleeding Disorder Caregivers Sheet

Place on Refrigerator – For Emergency Use & Daily Reference

BLEEDING DISORDER DETAILS	**Name of child/Loved One:**	
	Date of Birth	
	Diagnosis *(e.g., Hemophilia A Severe <1%, VWD Type 2)*	

BLEEDING DISORDER DETAILS	**Type:**	
	Severity:	
	Inhibitor status:	
	Product/Factor Name:	
	Dose:	units/kg
	Usual Infusion Schedule/ last prophy dose:	

EMERGENCY INFUSION PLAN Call your HTC nurse/provider 24/7	**Signs to Infuse:**	• Head injury or hard bump • Injury or accident to spine • Joint pain or swelling • Bleeding that does not stop after 10 minutes • Abdominal pain with unknown cause • Mouth/tongue bleeding that doesn't stop
	First Step:	
	Second Step (if no response):	
	ER/Hemophilia Center to call:	

MEDICATIONS Including Factor, Pain Meds	**Medication Name**	**Dose**	**Time Given**	**Notes**

ALLERGIES Factor, Medication, Food		

BLEED LOG Most Recent Bleeds	**Date**	**Location** (Joint, Muscle, etc.)	**Infused** (Yes or No)	**Notes**
	/ /		Yes / No	
	/ /		Yes / No	
	/ /		Yes / No	
	/ /		Yes / No	

EMERGENCY CONTACTS Call your HTC nurse/provider 24/7	**Name**	**Relationship**	**Phone Number**

HEMOPHILIA TREATMENT CENTER				
	HTC / Hematologist:		**Phone:**	
	Primary Care:		**Phone:**	
	Pharmacy (Specialty):		**Phone:**	
	Preferred Hospital / ER:		**Phone:**	

ADDITIONAL NOTES		
	Insurance Info:	
	Factor Location:	
	Emergency Dose Stored In: (fridge, cabinet, etc.)	
	Pump/Port Access Info:	

Download additional sheets here:
qrco.de/bgCQFZ

Bleeding Disorder Caregivers Sheet

Place on Refrigerator – For Emergency Use & Daily Reference

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ALLERGIES Factor, Medication, Food		

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	/ /		Yes / No	
	/ /		Yes / No	
	/ /		Yes / No	
	/ /		Yes / No	

EMERGENCY CONTACTS Call your HTC nurse/provider 24/7	**Name**	**Relationship**	**Phone Number**

HEMOPHILIA TREATMENT CENTER				
	HTC / Hematologist:		**Phone:**	
	Primary Care:		**Phone:**	
	Pharmacy (Specialty):		**Phone:**	
	Preferred Hospital / ER:		**Phone:**	

ADDITIONAL NOTES		
	Insurance Info:	
	Factor Location:	
	Emergency Dose Stored In: (fridge, cabinet, etc.)	
	Pump/Port Access Info:	

Download additional sheets here:
qrco.de/bgCQFZ

Timeline for Bleeding Disorders

1977-Today

1977

Desmopressin (DDAVP) identified to treat mild hemophilia and von Willebrand disease

1982

CDC reports first AIDS cases among people with hemophilia

1983

CDC links spread of AIDS to infected blood

Heat treatment found to kill HIV virus in blood products

1984

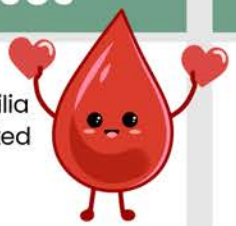
First inactivated (heat treated) factor concentrates available

1985

Ryan White barred from school

1989

World Hemophilia Day started



1992

FDA approves first recombinant FVIII products

1994

Hemophilia Federation of America (HFA) is founded

1995

Prophylaxis becomes standard of treatment in US

1997

FDA approves first recombinant FIX products

1998

Ricky Ray Hemophilia Relief Fund Act passes

First human gene therapy trials begin

2010

Patient Protection and Affordable Care Act Signed

2014

First extended half-life products for FVIII and FIX released

2017

HEMLIBRA is approved for FVIII inhibitor patients (2018 for non-inhibitor patients)

2020

COVID-19 Pandemic Begins

2022

Hemophilia gene therapy conditionally approved in Europe

Nov 22, 2023

Gene Therapy product for hemophilia B approved by FDA for use in the United States.

June 29, 2023

Gene Therapy product for hemophilia A approved by FDA for use in the United States.

HEMOPHILIA
OUTREACH CENTER

hemophiliaoutreach.org
info@hocgb.org
1-800-992-6026