

von Willebrand
Disease

ACTIVITY BOOK



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

KIDS WITH VWD CAN AND SHOULD PLAY...



△ CAN YOU FIND AND COLOR
THE SAFETY GEAR ORANGE?



BUT PLEASE PLAY SAFE.

CAN YOU FIND AND COLOR
THE SAFETY GEAR BLUE?



**TELL A GROWN UP IF YOU
GET HURT OR SOMETHING
FEELS BAD. SHOW AN ADULT
YOUR MEDICAL ALERT ID.**

**HELP THE KIDS FIND
THEIR SAFETY GEAR
AND MAKE IT TO THE
SOCCER GAME!**





LOOK CLOSELY AT THE SCENE. CAN YOU FIND AND CIRCLE THE OBJECTS BELOW?



BANDAGE



BICYCLE HELMET



FACTOR INFUSION SYRINGE



RED CROSS



GOLF CLUB



BALL



SWIM GOGGLES

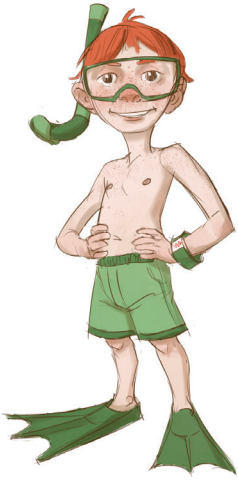


NASAL SPRAY

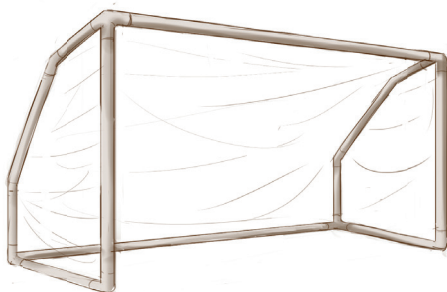
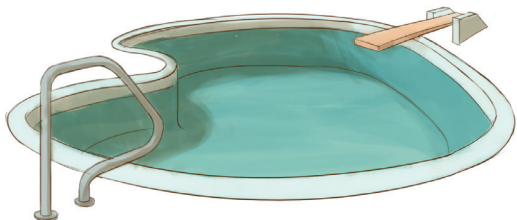


MEDICAL ID BRACELET

Match the Kid & Activity



**CAN YOU MATCH EACH KID WITH AN ACTIVITY?
DRAW A LINE TO THE CORRECT ANSWER!**



TURN THE PAGE FOR ANSWERS!

KIDS & THEIR ACTIVITIES!



1 7 year old Emmett has VWD and loves swimming.

2 9 year old Gabby has diabetes and loves to read.



3 8 year old Drew has asthma and loves to play soccer but has to use his inhaler sometimes.

4 6 year old Ramona has food allergies. She loves gymnastics and ballet, and eating ice cream.



5 10 year old Samara has VWD and loves to go camping and hiking with her family and dog.



6 10 year old Michael has no medical issues but doesn't like to play sports and feels left out sometimes. He does love to draw.



Everybody feels like they have something different going on with them sometimes. You can't always tell by looking at a person. Make new friends, include others, and stand up for what is right.

WHAT DO THESE HAVE TO DO WITH YOUR BLEEDING DISORDER? ASK AN ADULT!

Find these words!

Bleed
Bruise
Coaches
Factor
Friends
Golf
Hematologist

Hiking
HTC
Infusion
Joint
Nose Bleed
Nurse
Physical Therapist

Social Worker
Support
Swim
Teachers
Von Willebrand
Disease
VWF

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

Test Your Bleeding Disorder Smarts!

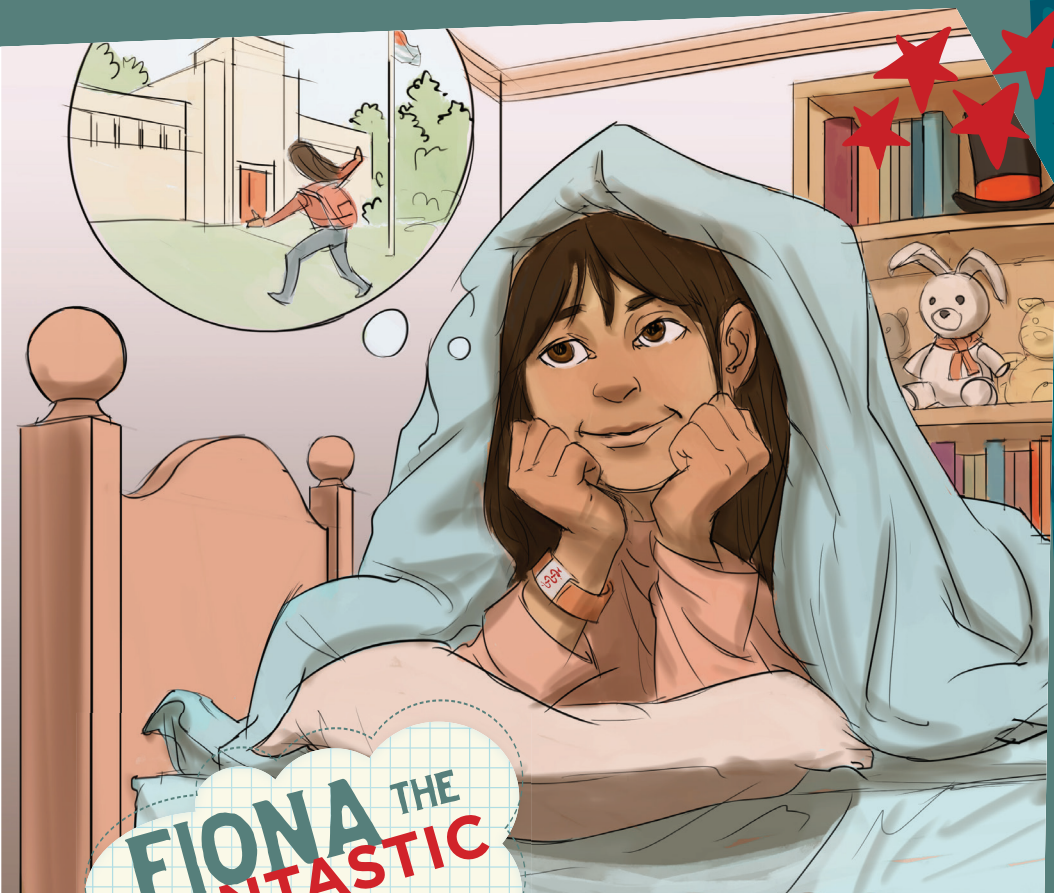
MYTH OR FACT?

- 1 Only girls have VWD.
- 2 VWD is one of many different bleeding disorders.
- 3 Hemophilia is the most common bleeding disorder.
- 4 Name 4 common symptoms of VWD.
- 5 People with bleeding disorders can die from a paper cut.
- 6 You can “catch” a bleeding disorder from a friend.
- 7 Many people in one family can have VWD.
- 8 A bleeding disorder is a type of cancer.

FIND OUT MORE ABOUT YOUR BLEEDING DISORDER
AT STEPSFORLIVINGHEMOPHILIA.ORG

ANSWERS

1. **Myth:** Boys have VWD too, in equal numbers as girls do. 2. **Fact:** Other bleeding disorders include hemophilia and rare factor deficiencies. Each of these bleeding disorders has a different type of clotting factor in their blood that is missing, in low levels, or not working right. Clotting factors are proteins in the blood that control bleeding. If any of the clotting factors is missing or not working properly, bleeding continues for longer than it should. 3. **Myth:** VWD is the most common (about 1% of people in the US). Some people have more bleeding than others, regardless of having VWD or hemophilia. 4. Easy bruising, lots of nosebleeds that last a long time, lots of bleeding after surgery or dental work, heavy periods in girls 5. **Myth:** People with bleeding disorders can have life threatening complications but won't die from a paper cut or any other scrape. As they say “we bleed longer, not stronger.” With proper treatment, people with bleeding disorders live long, healthy, active lives. 6. **Myth:** Bleeding disorders are not contagious (which means you can't catch them by just being around someone who has one). Most are inherited, which means it was part of your family genes or make up, but some people are born with a bleeding disorder without anyone in their family having one. 7. **Fact:** Most bleeding disorders are inherited, which means it was part of your family genes or make up. Some kids have a lot of family members (parents, siblings, aunts, uncles, grandparents) who have a bleeding disorder. For other kids, they may be the only one in their family that they know that has a bleeding disorder. Even if many people in one family have a bleeding disorder, each individual may have different symptoms and treatment. 8. **Myth:** Bleeding disorders are not cancer. Some doctors who treat kids with a bleeding disorder also treat kids who have blood cancer, so you may end up meeting kids with different health issues when you go to the doctor.



FIONA THE FANTASTIC

Fiona peeked out from under her blanket. The sun was just coming up and the birds were tweeting outside her bedroom window. She jumped out of bed and grabbed her book bag. There was going to be a magician at the school assembly today and there was no way she was going to miss it. "Hold on there, young lady! Aren't those the same clothes you wore yesterday?" her mom asked as Fiona grabbed an apple and ran toward the front door.

"No time, Mom! Gotta go!"

Fiona was so excited when she got to homeroom, she could hardly sit still. Her teacher, Mr. Morrow, noticed her fidgeting in her chair. "Looking forward to the assembly today, Fiona?" he asked.

“Of course!” she exclaimed, “I saw this magician once who cut a woman in half and then put her back together!” Mr. Morrow just chuckled.

Suddenly, Fiona smelled something funny yet familiar. Oh no! she thought, wiping her nose with her finger. Not a nosebleed—not now! She got up to get a tissue when her friend Paul saw the blood.

“Are you OK?” he asked, and several other kids turned to see what was going on. Fiona blushed—how embarrassing!

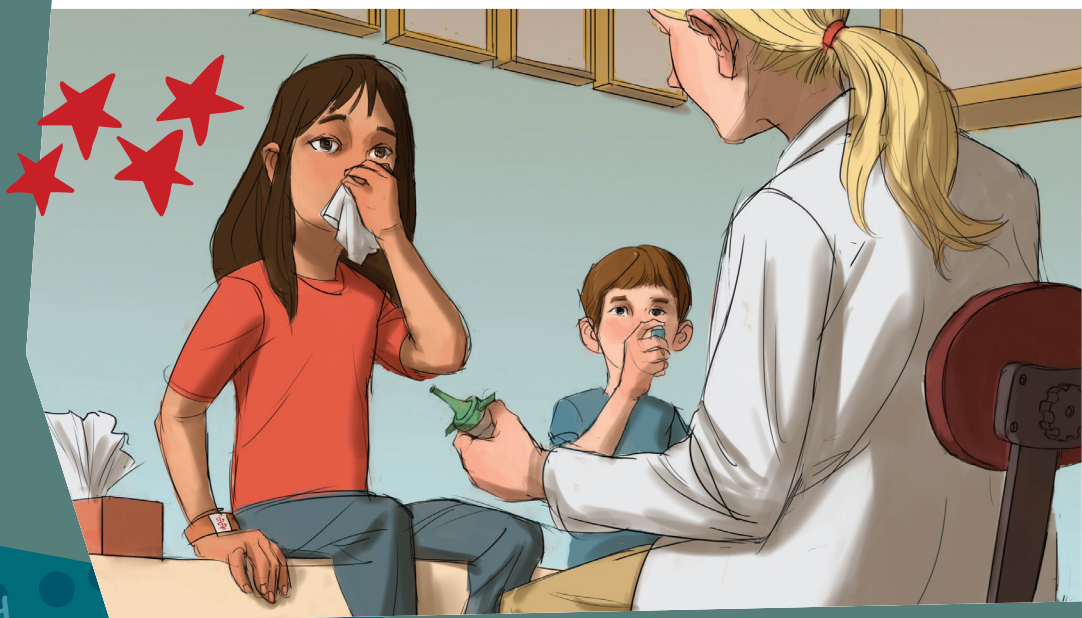
Mr. Morrow saw the commotion. “I think I’d better go to the nurse’s office,” Fiona told him.

“Of course!” he said, offering her a handful of tissues.

At the nurse’s office, Miss Breen handed Fiona more tissues and had her sit down. “Pinch your nose and hopefully it will stop—and try to calm down. I will go get your medicine.”

But Fiona was too worried. “If it doesn’t stop, I’ll miss the magician!”

Miss Breen tried to get her mind off of the nosebleed.



“Can you do any magic tricks?” She asked Fiona.

“I wish! Last summer I saw this magician who pulled a rabbit out of a hat! I asked him how he did it, but he said that a magician never reveals his secret. I want to be a magician some day—Fiona the Fantastic!—then I’ll be able to pull a rabbit out of a hat and keep it as a pet!”

Miss Breen smiled. “Where was the magician performing?” she asked.

“At this walk for people with hemophilia and stuff. But I don’t have hemophilia. My brother and I have this other thing—von Willebrand disease. It makes us get lots of nosebleeds and bruises. At least, that’s what our doctor told us,” Fiona said, grabbing a new tissue.

Miss Breen nodded, “Your mom told me a little about it when she brought in your DDAVP medicine. She gave me a pamphlet about it.”

Just then, Ethan walked into the nurse’s office and leaned against the wall. “I need my inhaler, Miss Breen,” Ethan gasped.

As the nurse got up, Fiona noticed that Ethan had a bracelet just like hers, except his was blue. “Hey, I have a bracelet just like that,” Fiona said, raising her wrist up in the air.

Ethan looked at the bloody tissue in her hand. “Ewww...are you going to bleed to death?”

Fiona looked puzzled. “No...my doctor said that I just bleed longer than other people,” she said as she grabbed a new tissue. She pressed it against her nose and then looked at it. “I think it might be slowing down!” Fiona yelled. She looked up and saw Paul peeking his head in the door.

“Hi Miss Breen—I just wanted to make sure Fiona was OK,” Paul asked.

Miss Breen waved him in, “She’ll be fine.”

Paul sat down by Fiona. "The class is heading down to the assembly. Mr. Morrow said I could check in on you."

"I just have to take my medicine," she said as the nurse handed her the nosespray bottle.

Confused, Paul looked at the bottle. "What's that for?" he asked.

Fiona squirted it up her nose and took a deep breath in. "It helps me stop bleeding when I get a nosebleed," she said, "because I have von Willebrand Disease. See?" She flipped over her medical alert bracelet.

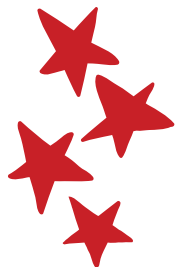
Paul looked at the writing on the back. "I didn't know that. I guess I never paid attention to your bracelet."

Fiona pressed a tissue up to her nose again. "Well, I didn't want to tell anyone because my brother told a couple of his friends and they made fun of him, and I was afraid..."

Paul interrupted, "I would never pick on you—you're Fiona the Fantastic! And I'm going to be your magician's assistant!"

Looking to Miss Breen, Fiona smiled. "Can I go now? My nosebleed has stopped!"

Fiona and Paul walked into the assembly just in time for the magic show. Paul turned to her and laughed, "If the magician needs a volunteer to be cut in half, maybe it's better you don't raise your hand."



FIONA THE
FANTASTIC

FIONA THE
FANTASTIC

Glossary

Bleeding disorder: A problem in the body where a person's blood does not clot properly.

Diagnosis: Identification of an illness or medical issue.

DDAVP: Desmopressin acetate, also known as DDAVP, is medicine that helps the body form a stable, firm clot. It is one type of medicine for VWD and either is taken by injection or a nose spray.

Doctor's letter: An official letter from your doctor that describes your bleeding disorder and medical needs in case of an emergency. You may need this when traveling or for sports.

Factor: Sometimes people say "factor" when talking about "factor replacement therapy" or "clotting factor." It is one type of medicine for VWD. Basically, you're giving your body the type of protein it needs to help your blood clot normally. Not all people with VWD use factor. Factor is given by infusion into a vein. The amount of factor you need depends on several things including your weight, where the bleed is, and if it's where you usually get a bleed.

Hematologist: A doctor who is an expert in blood problems. The hematologist may be your main doctor.

Hemophilia: An inherited bleeding disorder in which the blood does not clot properly. Blood contains many proteins (called clotting factors) that help stop bleeding. These clotting factors are numbered from 1 through 13, using roman numerals (such as I or X). People with hemophilia have either a low level of these clotting factors in their blood or none at all. The lower the level, the more likely the person will have bleeding problems.



HTC: HTC is short for hemophilia treatment center, where people with many different bleeding disorders see their doctors, nurses, physical therapists and social workers to get care for their bleeding disorder.

Infusion: This is one way of getting medicine into the body. It involves the medicine getting into the body directly into a vein, usually using a needle.

Inherited: Passed to the child through the parent's DNA.

Joint bleed: Bleeding into the space between two bones. Elbows, knees and ankle are joints that often get bleeds.

Medical Alert ID: A tag, often worn as a bracelet or necklace, with information about any medical issues the person wearing it has. It helps get the person the proper care in case of an emergency.



Physical therapist (PT): Trained healthcare providers that help patients reduce pain and improve how their bodies move. They also show their patients how to prevent future injuries.

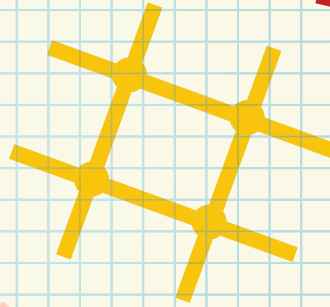
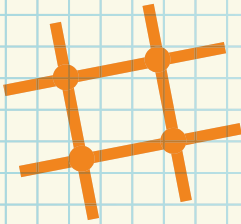
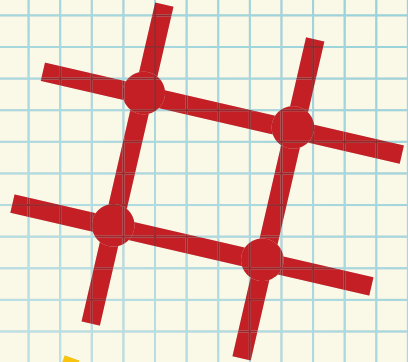
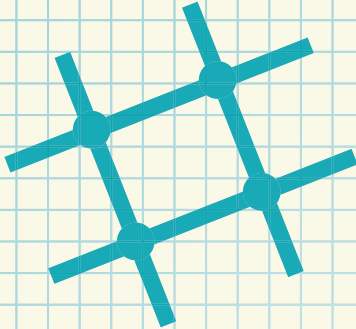
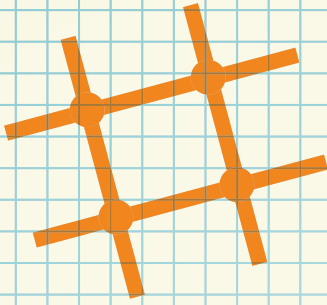
Social worker: A social worker helps a person with a bleeding disorder and his or her family handle everyday problems that can come up when living with a bleeding disorder. A social worker is a good person to talk to if you feel sad, worried or anxious about your bleeding disorder.

Symptom: A sign, such as pain or a bruise, that signals that something in your body isn't right. By telling a doctor your symptoms, it will help him or her figure out what is wrong.

Treatment: The medical care given to a patient for an illness or injury.

Von Willebrand disease: von Willebrand disease (VWD) is a disorder that is caused by a problem with one of the proteins in the blood (von Willebrand factor or vWF). People with VWD either don't have enough vWF or what they have doesn't work properly.

TIC TAC TOE



NATIONAL HEMOPHILIA FOUNDATION

for all bleeding disorders

For more information on living with
a bleeding disorder, go to
stepsforliving.hemophilia.org



STEPS FOR LIVING
Education for all life stages.

This activity book is sponsored by
octapharma[®]

The National Hemophilia Foundation 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. 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).