ADVENTURES WITH MY Bleeding Disorder

Innovative Hematology
Indiana Hemophilia & Thrombosis Center

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Special thanks to IHTC staff—past and present.

WELCOME TO Innovative Hematology

Indiana Hemophilia & Thrombosis Center

This book is for kids like you who are patients of Innovative Hematology and the Indiana Hemophilia & Thrombosis Center (IHTC). You visit this center because you are a kid living with a bleeding disorder. This book was made by your IHTC team to help you learn about IHTC and bleeding disorders.

This is YOUR book! You can draw and write in it, and take it home with you!

MY PAGE

My name is _____.

I am _____ years old.

I am from _____.

My favorite things about me are _____

_____

My family members are

_____

_____

When I grow up, I want to be a _____.

Doctor

The Doctor is in charge of your care. They decide what kind of medicine will help you feel better, or if you will need to go to the hospital. They see you in the clinic and ask you how you are feeling—and if you have questions about your bleeding disorder.

Physician Assistant or Nurse Practitioner

The Physician Assistant or Nurse Practitioner works with the Doctor and may see you in the clinic. They ask you questions about your bleeding disorder to help understand how you are feeling. They make a plan to help you stay healthy and feel better.

Nurse

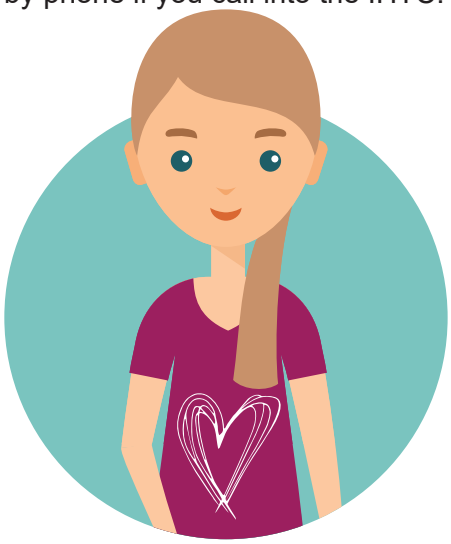
The Nurse checks you into your room. They check your height, weight, temperature and blood pressure. They may give you medicine to help you feel better if you need it. They teach you and your family how to infuse. They are also available to answer questions by phone if you call into the IHTC.

School / Career Counselor

The School/Career Counselor will see you in clinic and may also visit you at home or in school. They teach you and your family how to talk to others about your bleeding disorder. Sometimes they visit your school to teach your teachers and the school nurse about your bleeding disorder.

Social Worker

The Social Workers help you and your family with questions about where to get medicine and insurance. They also help you find ways to feel better if you are feeling sad or mad. They are easy to talk to and want to help you understand your bleeding disorder.



Child Life Specialist

The Child Life Specialist helps you understand your bleeding disorder and the things done at the clinic. They can help you find things to do when you are scared or in pain and help you feel better. *They like to have a lot of FUN, too!*

Physical Therapist

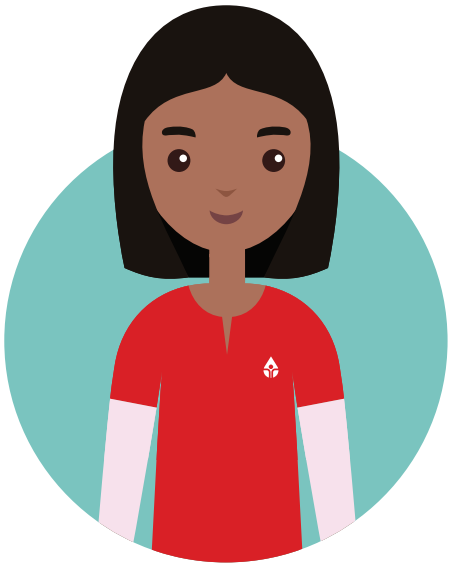
The Physical Therapist will see you in clinic if you are having a problem with your bleeding disorder. Sometimes they look at your elbows, knees, and ankles with the Ultrasound so they can see what they look like inside. You have to sit still and the jelly is cold, but it doesn't hurt at all.

Pharmacy Team

The Pharmacy Team helps make sure you have the right medicine at home for YOUR bleeding disorder. They also teach you how to write down your medicines and when to order more so you don't run out.

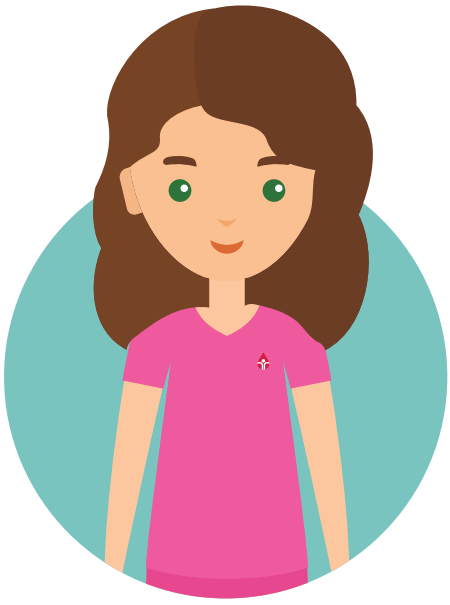
Dietitian

A Dietitian will meet with you and your parents in the clinic and talk with you about the foods that you like to eat. They will teach you what foods have a lot of vitamins and are good for you and what types of foods you should be eating to grow big, strong, and healthy.



Research Team

The Research Team will tell you about ways you can help can help other people with bleeding disorders. One way you may be able to help is through a study. Studies help us learn more about your bleeding disorder.



Dental Hygienist

A Dental Hygienist may meet with you and your parents in the clinic and talk with you about brushing your teeth and if you have been to the dentist. They will teach you how to brush and things to watch for with your bleeding disorder.

Genetic Counselor

The Genetic Counselor might see you in clinic and ask you and your family about your whole family and if they have had any bleeding like you. They help to find out if anyone else in your family has a bleeding disorder too.

Who is your IHTC Doctor?

Phone: 1-800-CLOTTER **Website:** www.InnovativeHematology.org
Address: 8326 Naab Road Indianapolis, IN 46260

What is a clot and why is it important?

When a person gets hurt or has a nose bleed, the blood needs to make a clot so that the bleeding stops. A clot is like a strong wall that keeps the blood where it is supposed to be. The bleeding can be on the outside where you can see it (like a nosebleed), but it can happen on the inside too, where you can't see it.

Something is missing

When you have a bleeding disorder, it means that your blood doesn't always work the way it is supposed to. You might have a lower amount of a certain factor. Factor is a part of your blood; it helps you make a clot. When you have lower levels of factor, it takes longer for you to stop bleeding than it should. If you have hemophilia, you have lower levels of factor 8 or factor 9. If you have von Willebrand Disease, you have lower levels of VWF. Sometimes when you have low factor levels, that factor needs to be added back in to your blood. This is an infusion.

Do you know which factor you have low levels of? _____

FACTOR 1

FACTOR 5

VWF

FACTOR 13

FACTOR 8

FACTOR 2

FACTOR 9

FACTOR 11

FACTOR 7

FACTOR 12

FACTOR 10

WHICH ONE OF YOURS IS LOW?

MY FAVORITE THINGS

My favorite television show is:

My favorite place is:

My favorite team is:

My favorite color is:

Here is a picture of my favorite thing to do:

WHAT I WANT YOU TO KNOW

When I am happy, I like:

When I am scared, I want:

When I am hurting, it is hard to:

I am great at:

Some other things I want you to know about me are:

ABOUT SCHOOL

Where I go to school:

What grade I am in:

The best thing about school is:

The worst thing about school is:

What I am good at in class:

What is hard for me in class:

Here is a picture of me in class:

This is what I think my bleeding disorder looks like:

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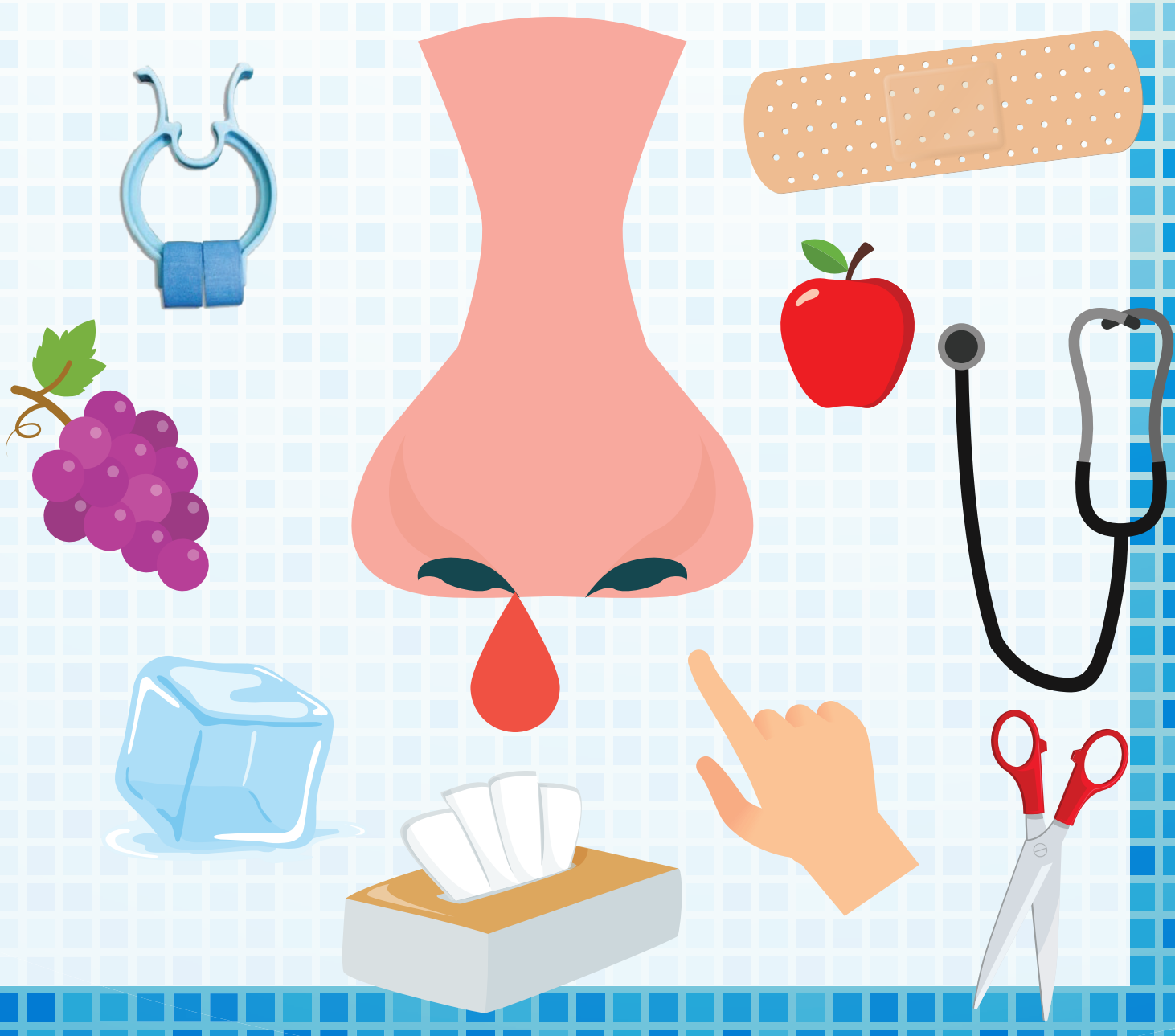
What should I do when I have a nose bleed?

Sometimes it is scary when your nose bleeds. There are a lot of different ways to help it slow down or stop. If you have a nose bleed, you should let an adult know so that they can help you get it to stop. Holding pressure on your nose and putting ice on your nose can help slow down your nose bleed sometimes. Sometimes you need a soft clip on the outside to help it stop.

If you have a lot of nose bleeds really close together, or if they last a really long time, you and your family should call the IHTC to see if you need to see a doctor or if you need medicine to help stop the nose bleeds.

Below, there are some things that can help slow down or stop a nose bleed. Draw a line from the nose to the things that will help it stop bleeding.



Who should I tell when I get hurt?

You should know when to tell someone that you have been hurt. It is very important to let an adult know when you get hurt, especially if you hit your head, you are bleeding or have swollen knees, ankles or elbows that hurt. You should tell someone as soon as possible, even if you are at school or at a sports practice. Your teachers and coaches can help.

Who would you tell if you were at home?

_____

_____

Who would you tell if you were at school?

_____

_____

What should I do if I get hurt?

Tell Someone

Medicine or Infuse if needed

Call the IHTC

R.I.C.E

Call to see the Doctor and PT

THINGS TO REMEMBER WHEN I HAVE AN INJURY

Physical Therapy

The Physical Therapists (PTs) at IHTC help a lot when you get hurt. They use a special machine called an Ultrasound (US) to be able to see inside your joints and muscles. The US doesn't hurt but does use a cold jelly and really cool wand to show the inside of your joints and muscles on a computer screen. They can show you the difference between a hurt joint or muscle and a healthy one. They even let you help put on the jelly!

PTs help in other ways too. They show you stretches and exercises to help make your joints and muscles stronger. They also tell you when to rest and not do too much activity if your joint or muscle needs to heal. Sometimes they use a funny thing to measure how far your joints can bend and straighten. They are measuring your Range of Motion.

R.I.C.E.

R.I.C.E. helps you and your family to remember to do these things when you have an injury to a joint or muscle:

✓Rest

Take it easy when you are hurt, stay off your feet

✓Ice

Put ice on the place that is hurting to help it feel better

✓Compression

A parent or PT may wrap your muscle or joint very tightly with a bandage or put a brace on it. This will help you feel better and make your joint or muscle get smaller if it was swollen because of your injury.

✓Elevate

It is important to keep the place that hurts above your heart. (ex. Ankle—lay down with your feet propped up on the arm of the couch, Elbow— lay your arm on pillows when sitting in chair).

WHAT DID THEY SAY?

I.V. (Intravenous)
A small bendable tube that stays in a vein to give medicine and fluid.

Hospital
A place where you go if you are having bad pain, have been in an accident, or a fever.

Hemophilia
A health condition caused by missing a factor in the blood. Your blood doesn't clot as well, so it sometimes takes longer to stop bleeding.

Joints
Places on your body where two bones meet and bend, like your knees, ankles and elbows.

Factor
A part of a protein that helps your blood form a clot. It takes factors and VWF to make a clot.

Infusion
This is when you replace the missing factor. The medicine is infused into your vein by a type of I.V.

Infection
When germs grow in the body and make you sick.

PUT ME IN, COACH!

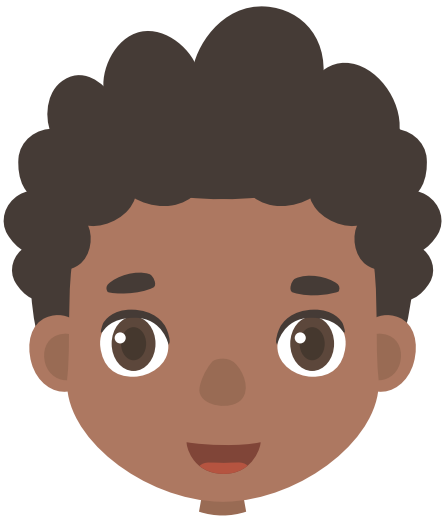
Draw a picture of the sports and activities you like to play.

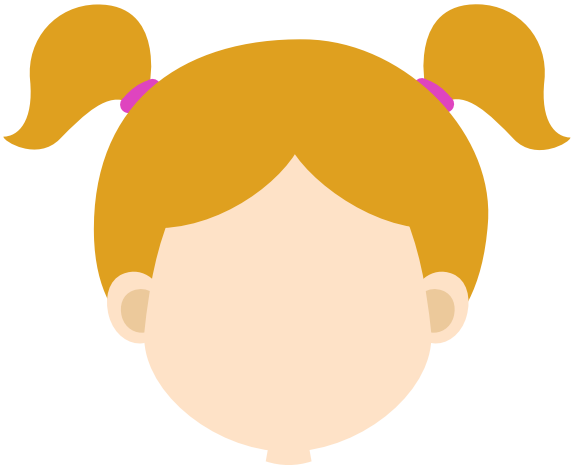
We know that sports and activities are fun—they are important to stay active to keep yourself healthy. Always let your coach or gym teacher know about your bleeding disorder in case you have a nose bleed or get injured while playing.

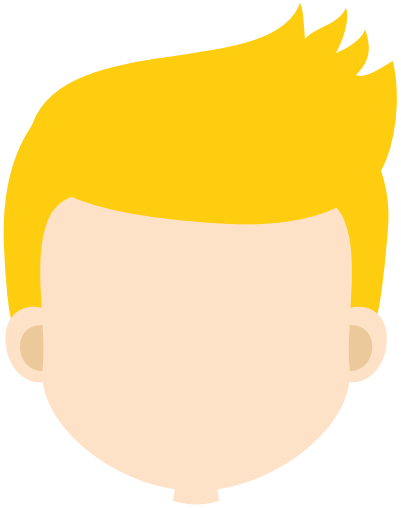
MY FEELINGS

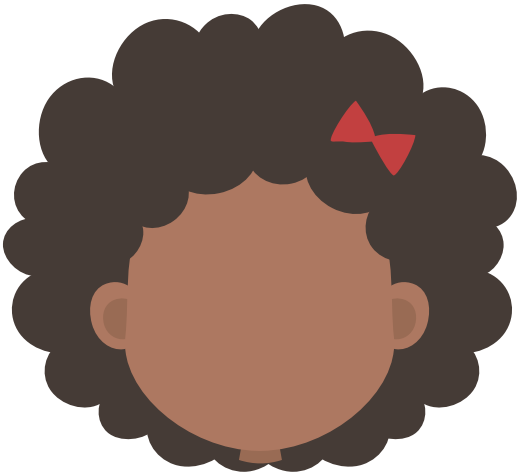
How do you feel when you think about your bleeding disorder? Show us by drawing faces for our friends below.

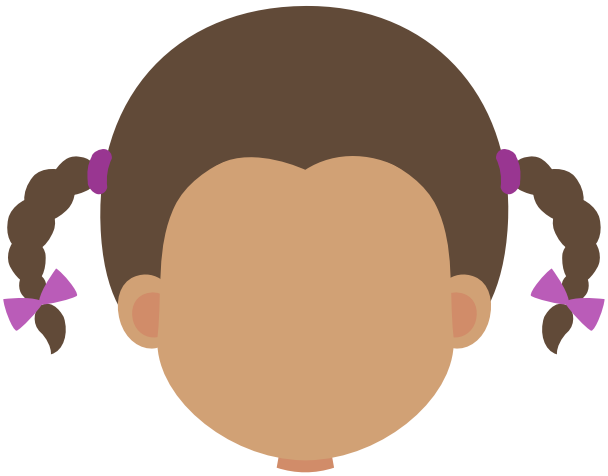
When I think about my bleeding disorder, some of the feelings I have are:

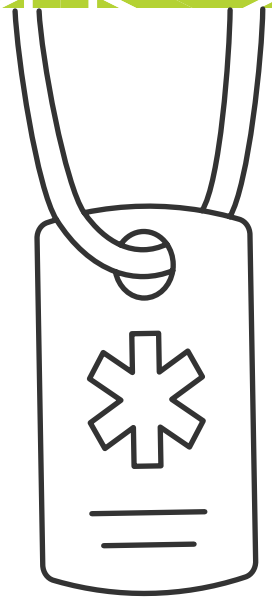












My Medic Alert

It is very important that you wear your medic alert at all times. They come in all kinds of styles like bracelets and necklaces. They even come in really cool colors! You get to pick which one you like the best (and the color)! Even though your medic alert looks really cool, more importantly it lets people know very important things about you and your bleeding disorder, like your name, birthday, how to reach your mom and dad, what bleeding disorder you have, and what kind of medicine you use. When you wear your medic alert, it tells people that they need to know more if you get hurt. It is very important to wear your medic alert all the time. No matter where you are, what you are doing, or who you are with, you should *ALWAYS* be wearing your medic alert.

What does your medic alert look like? Draw it here!

CAMP BRAVE EAGLE

"Where the eagles soar!"

IHTC wants you to come to camp and have a lot of fun!
Camp Brave Eagle is a week-long overnight camp where you get to meet other kids who have bleeding disorders just like you.
You will also get to hang out with IHTC and Camp Brave Eagle Staff.

There are lots of fun activities at Camp: swimming, climbing, boating, and meeting lots of new people. It is a GREAT TIME!!!

What would you like to do at camp?
Draw your favorite camp activities!

THINGS I'VE LEARNED AT IHTC

Circle the words you see below.

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

~~BLEED~~
BRAVE
CAMP
CELL
DOCTOR
EAGLE
EIGHT
FACTOR
HEMOPHILIA
INFUSION
NINE
PLATELET
RED
REST
WHITE

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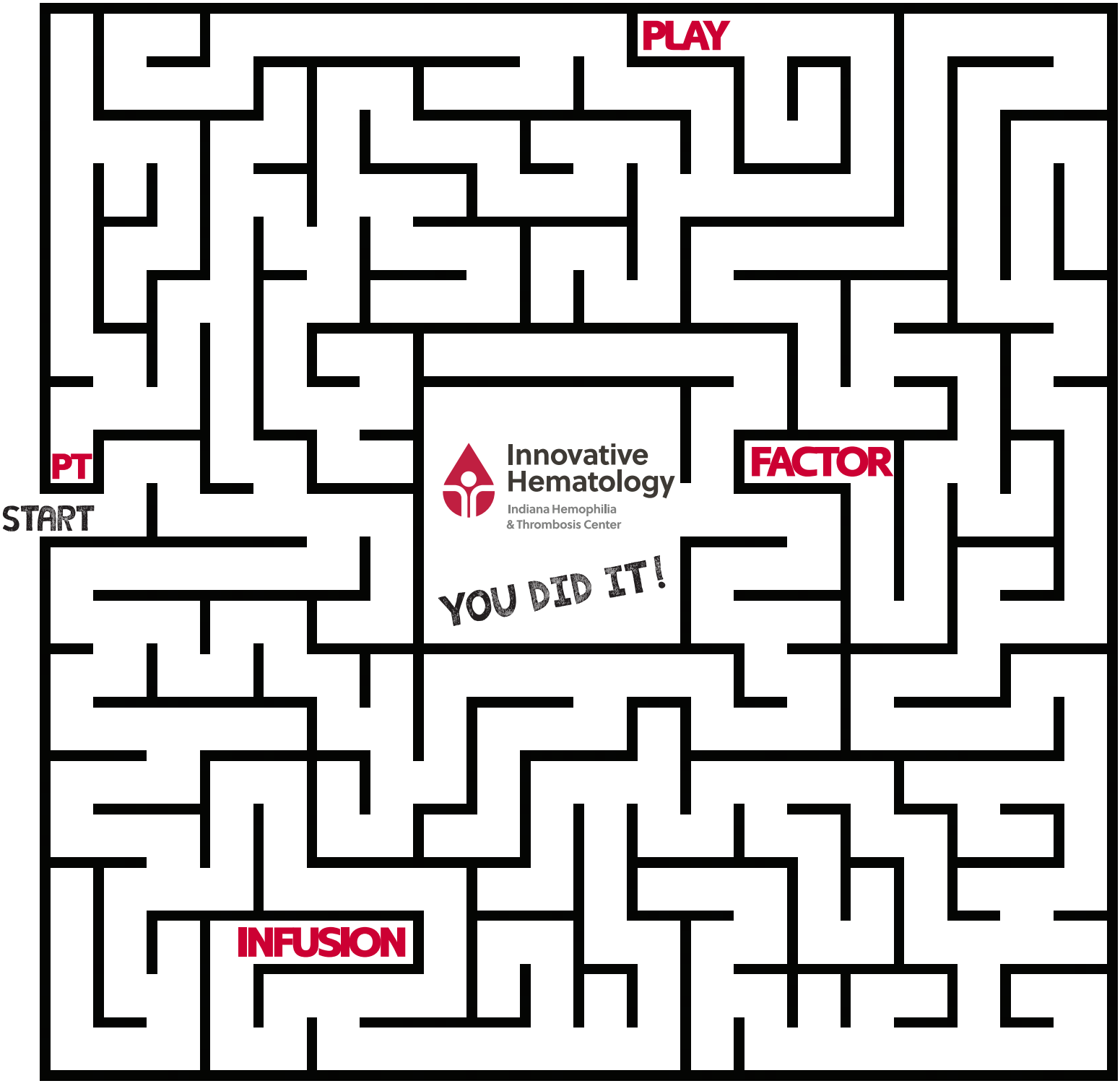
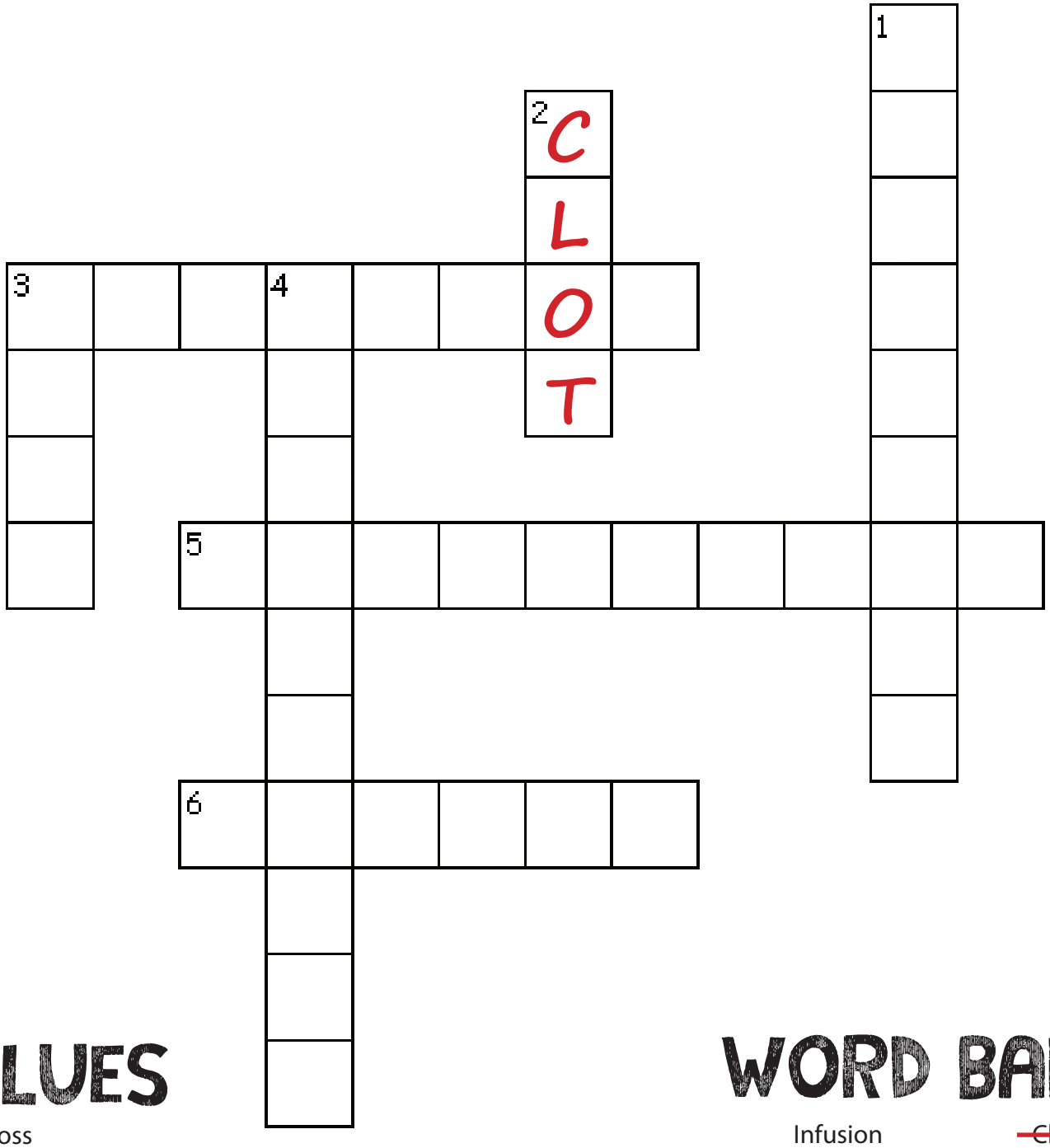
IHTC . . . WHAT A PLACE!

IHTC is a big place, and lots of things happen here.
It can be confusing!
See if you can make it through the IHTC maze to the finish.



CROSSWORD PUZZLE



CLUES

Across

3. How do you get factor?
5. What is the name of our camp?
6. Who is in charge of your care?

Down

1. Who can help you talk to your school about your bleeding disorder?
2. When you have a bleeding disorder, your blood has trouble making a ___?
3. What is the name of our center?
4. How does PT look inside your joints?

WORD BANK

Infusion	~~Clot~~
Child Life	Doctor
Pharmacist	Counselor
IHTC	Ultrasound
Brave Eagle	Factor

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QUESTIONS AND ANSWERS

Why do I have to come here?

The IHTC wants to make sure you are feeling good and that your blood is working the way it should.

Why do I have to have blood draws?

The IHTC checks your blood to make sure your medicine is working and you don't need any other medicines.

Why do I have to infuse?

Your body needs extra help to replace your low amounts of factor. It is important to not miss any of your infusions so you can stay healthy and strong.

Can people get a bleeding disorder from me?

No, people cannot get your bleeding disorder from you. Bleeding disorders can be passed down in your family. Do you know anyone else in your family who has a bleeding disorder?

INFUSION LOG

Date	Reason	What product?	How much?	Where did you infuse?	Notes
Date	Reason	What product?	How much?	Where did you infuse?	Notes
Date	Reason	What product?	How much?	Where did you infuse?	Notes
Date	Reason	What product?	How much?	Where did you infuse?	Notes
Date	Reason	What product?	How much?	Where did you infuse?	Notes
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