

IN-HEMOACTION

PLAYING AND LEARNING
ABOUT HEMOPHILIA



WFH

WORLD FEDERATION OF HEMOPHILIA
FÉDÉRATION MONDIALE DE L'HÉMOFILIE
FEDERACIÓN MUNDIAL DE HEMOFILIA



This booklet and the In-HemoAction playing cards were developed by Frederica Cassis, volunteer psychologist at the Hemophilia Center at the Hematology Service of Hospital das Clínicas, FMUSP, Brazil, and are published by the World Federation of Hemophilia (WFH). The WFH and Frederica Cassis thank Marco Pavao for his design work.

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To play In-HemoAction online, to download free pdfs of the materials, or to order playing card game sets go to the WFH eLearning Platform:

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HOW TO USE IN-HEMOACTION

The In-HemoAction cards have a story to tell about important things you should know about hemophilia such as prophylaxis, immunotolerance therapy, inhibitors, the blood clotting process, sports activities, and a lot more.

In-HemoAction offers you the possibility to play and learn through different games such as:

1. **THE QUESTION AND ANSWER GAME** (for 2 or more players)

One player asks another what each picture means.
Whoever has the most right answers wins.



2. THE MEMORY GAME (for 2 or more players)

In this game, the goal is to find the highest number of pairs of cards by using your memory. Children starting at 3 years of age can play with a few pairs of cards or with those that they like the most! The player who finds the highest number of pairs wins.

The cards are shuffled and spread out face down. The first player turns over any 2 cards. If they are the same, he or she picks them up and plays again. If they are different, he or she leaves them where they were, face down. The next player then turns over two cards of their choice, and so on.

By using your memory (you can get better by practicing!), you can remember where the pairs are and find many of them.



3. THE “RUNNER” GAME (for 3 or more players)

This game uses 30 pairs of cards plus one unique card named the “runner”. On this card, a boy is shown running away from his hemophilia treatment. It is the only card without a number. The goal is not to have the “runner” card in your hand by the end of the game.

The 61 cards (30 pairs and one “runner”) are shuffled and dealt in turn to all the players, each person then puts any pairs he or she received on the table, face up. Whoever has the highest number of cards left in their hand plays first. He or she starts by picking a card from the hand of the player on his or her left. If the card makes a pair with another card in his or her hand, this new pair is also placed on the table. If he or she picks the “runner” card or another card that doesn’t make a pair, then it’s the next player’s turn.

Whoever gets the “runner” should try to get rid of it as fast as possible by mixing it in the middle of their own hand, so that the next player will pick it! In this game, whoever ends up with the “runner” loses.



LEARNING WITH IN-HEMOACTION

The cards may be used to teach about various topics related to hemophilia:

All the cards are numbered at the top so they can easily be identified. The following pages of this manual explain each picture on the cards. Different topics related to hemophilia can be explained by following a logical sequence. For example, some sequences that can be used to teach about specific topics are:

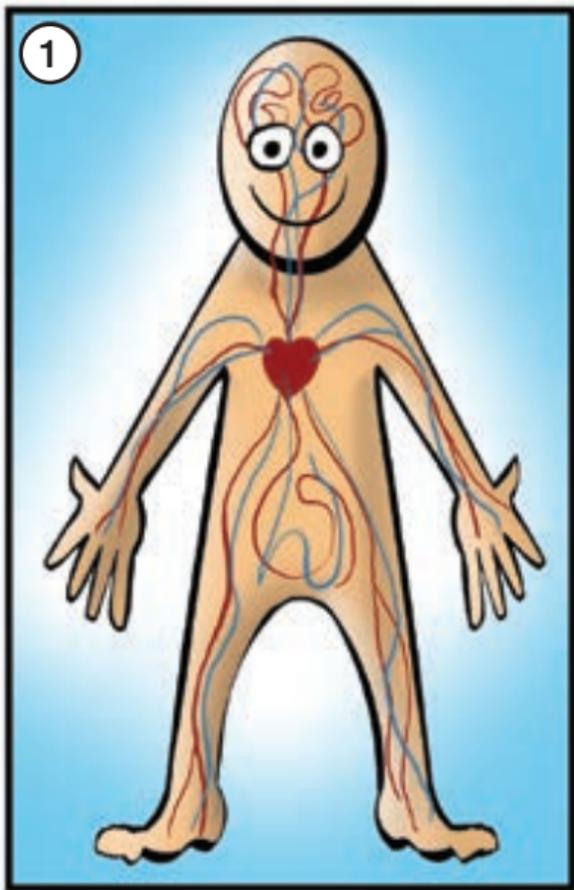
- **Types of injuries** (cards 4, 5, and 6)
- **First aid** (card 7)
- **The clotting process** (cards 4, 9, 10, 11, and 22)
- **The clotting process in hemophilia A and B** (cards 5, 9, 10, 11, 12, and 13)



- **The clotting process in a person with hemophilia infusing factor**
(cards 5, 8, 9, 10, 11, 12, 13, 14, 16, 17, and 18)
- **Prophylaxis** (cards 12, 13, 14, 15, 16, 17, and 18)
- **Benefits of prophylaxis** (cards 25, 27, 28, and 29)
- **Treatment to cancel out inhibitors – immunotolerance**
(cards 8, 19, 20, 23, 24, and 22)
- **Play and sports activities** (cards 25, 26, 27, 28, and 29)
- **Symbols to represent slowness in clotting and treatment**
(cards 13, 17, 21 and 23)
- **The importance of receiving factor quickly**
(card 17, turtle speeded up + card 16, boy self-infusing the factor + card 18, the vein healing + card 5, avoiding after-effects to the knee)

After using the cards for a while, the child will end up memorizing the meaning of each one of them.





Look at this!

Our whole body is linked together by internal tubes: they are the blood vessels!

These vessels carry blood to our entire body and are divided into three types: arteries, veins and capillaries.

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Do you want to see one of these vessels? Look carefully at the back of your hand: those are veins!

You can also find other veins in your arms...

Just open and close your hand a few times so you can see them more easily.





And do you know what runs inside your veins? Blood!

Blood is a red liquid that has a lot of important functions in your body.

One of them is “clotting,” which stops the bleeding when we hurt ourselves.

©



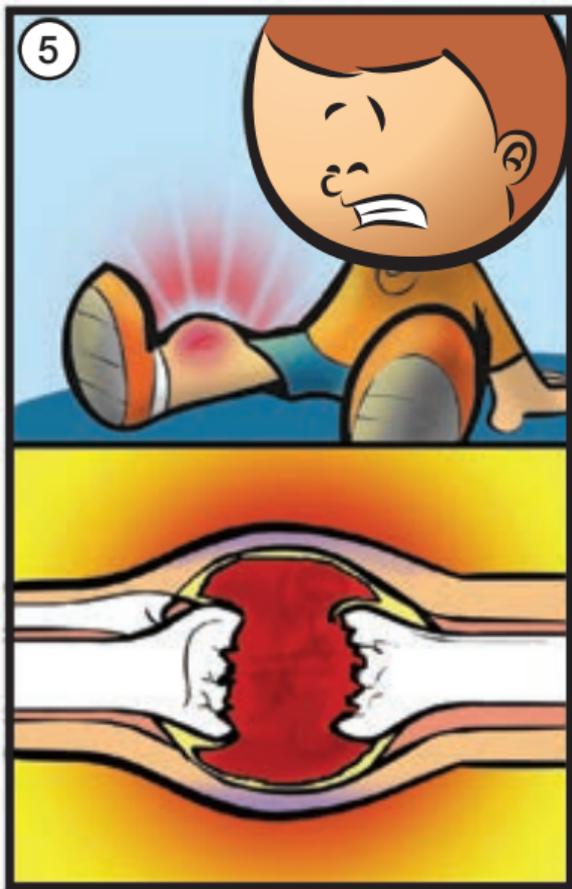
This is an **EXTERNAL** wound!

That means that the skin opened, the vein was broken and the blood inside of it comes out and we can see it.

Don't worry! The first thing to do is tell your parents or another adult nearby.

They'll help you with first aid and decide if you need to take the factor or not.





Here is another kind of wound.
See the boy's swollen, red knee?

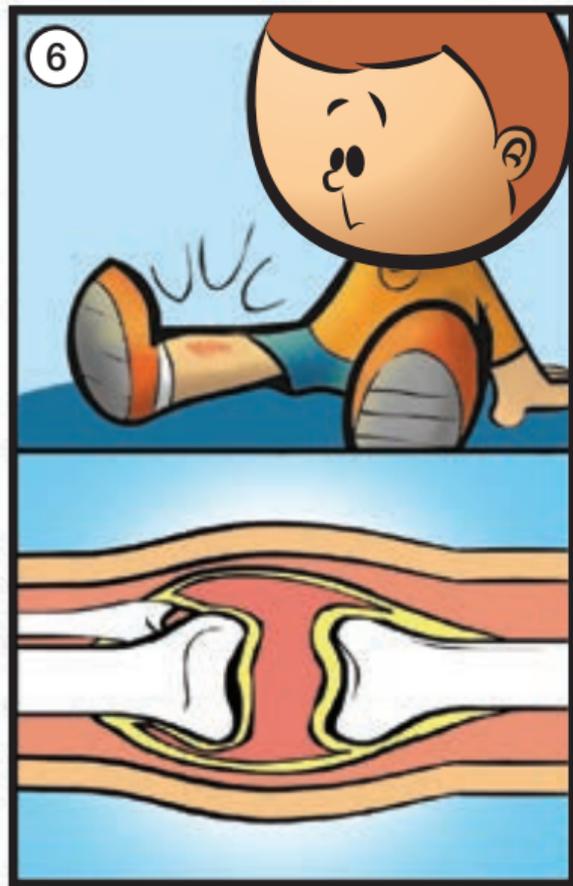
This is **INTERNAL** bleeding. The skin didn't open and you can't see the blood, but inside the vein is broken and blood is coming out!

If you take the factor right away, your knee will stop bleeding internally, the pain will go away and you'll get better faster. If not, the accumulated blood could damage the bone and cartilage inside your knee.



Here's a very light wound called an **ABRASION**.

His knee is just scraped a little, and it didn't bleed or swell up. In this case, you don't have to take the factor, because the little wound will get better by itself.





Attention!

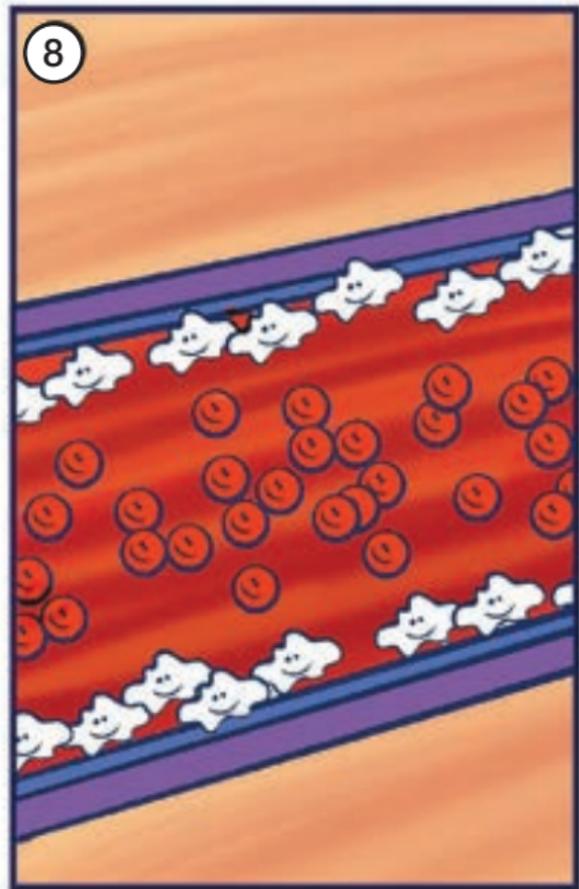
For all types of injuries to your skin (abrasions and cuts), you should always:

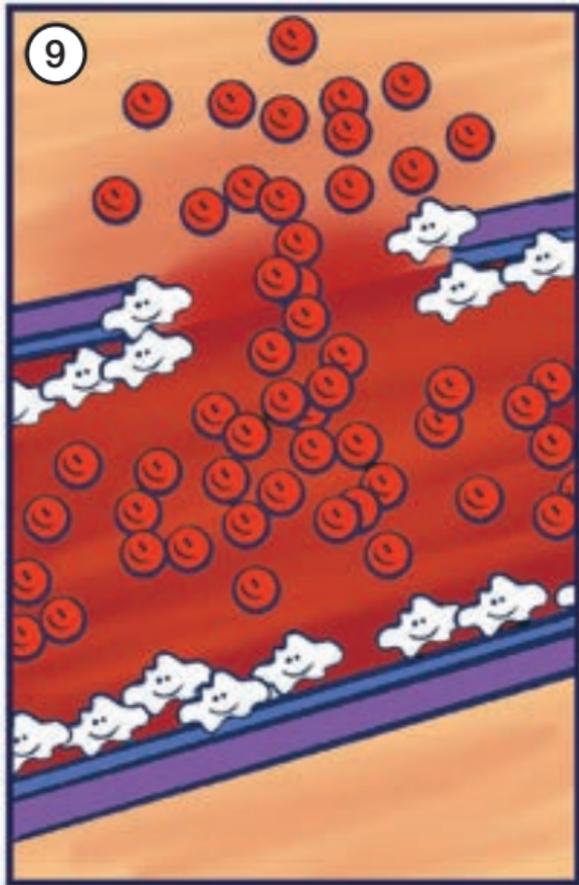
1. **WASH** the affected area with soap and water.
2. **PRESS** down on it with a clean cloth or gauze for a few minutes.
3. **APPLY** ice.
4. **PUT** a bandage on it.



You can see your veins
from the outside...

But what are they like inside?
Under the skin, veins are like tubes
with walls where the blood passes.
Blood has various kinds of cells.
Near the wall of the vein, there are
platelets. More in the middle of the
vein there are red blood corpuscles
which give blood its red color.

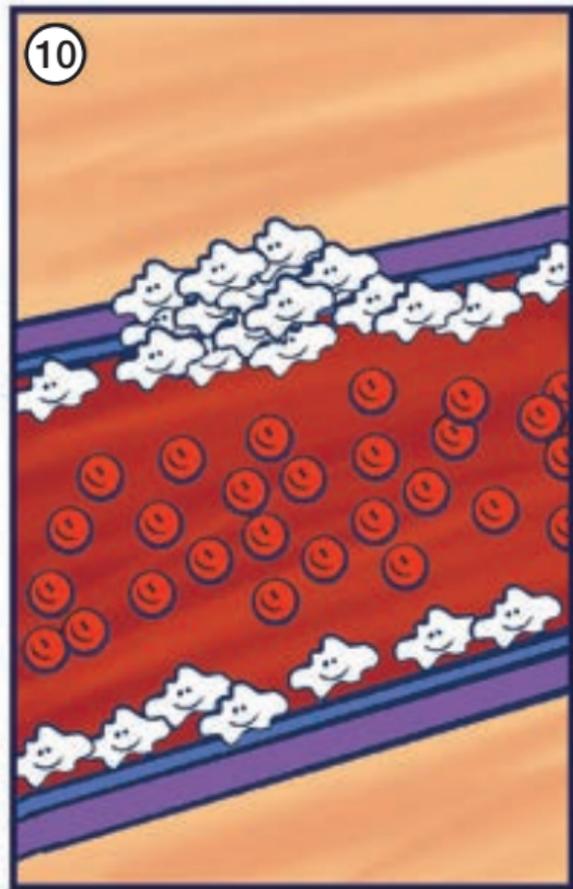




This is an external wound seen from inside, from the vein's point of view. The vein was broken and the blood is flowing out. This is the way bleeding starts.



The platelets are the blood cells that help to stop the bleeding. They come together quickly where the vein is broken to “plug” the hole and not let the blood get out. The name of this “plug” is the platelet plug, a reaction of the body that stops minor bleeding, such as the scraped knee. This reaction happens normally in people who have hemophilia, because they have the right amount of platelets.



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You still don't understand how the platelet plug works?

It's just like a sink stopper!

It works the same way: it doesn't let any more blood get out so that clotting can begin.

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If the injury is bigger, the bleeding won't stop with just the platelet plug. On top of the plug, a "net" will be made (the fibrin net) that will keep the blood in place so that the vein can mend. This is the clotting process! For people who have hemophilia, it takes a long time for this net to be made — and when it is formed, the clotting is neither firm nor strong. It's like in the picture: the formation of the net is weak and takes a long time, so the blood doesn't stop going out! This happens because one of the various factors needed to form the fibrin net is missing.





Look at the turtle, he is very hard working! But he is also very slow...

It's like the formation of the fibrin net in people with hemophilia A and B.

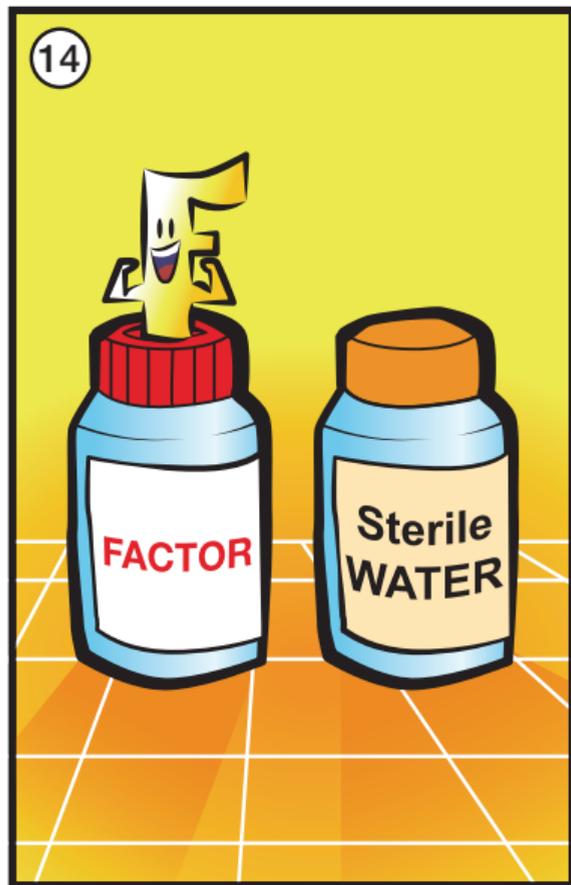
But the blood can't wait so long to clot! It's bad for joints and other parts of the body that can bleed. We have to do something!



The solution is the factor. Anybody who has hemophilia A should take factor 8 (FVIII) and those who have hemophilia B should take factor 9 (FIX). One of the vials has the factor concentrated into a powder and the other has sterile water.

We have to mix them together to make a solution that can be injected into the vein.

When people receive prophylaxis, when they infuse factor into their vein, it lasts for a few days but it does not last forever. To really prevent bleeding you need to always have some factor in your blood.



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See? Here's the factor -F- again. He is super excited about helping clotting to happen properly and in time. He can be number VIII (8) **OR** number IX (9). When he is injected into the bloodstream, he helps form a strong fibrin net which then stops the bleeding.

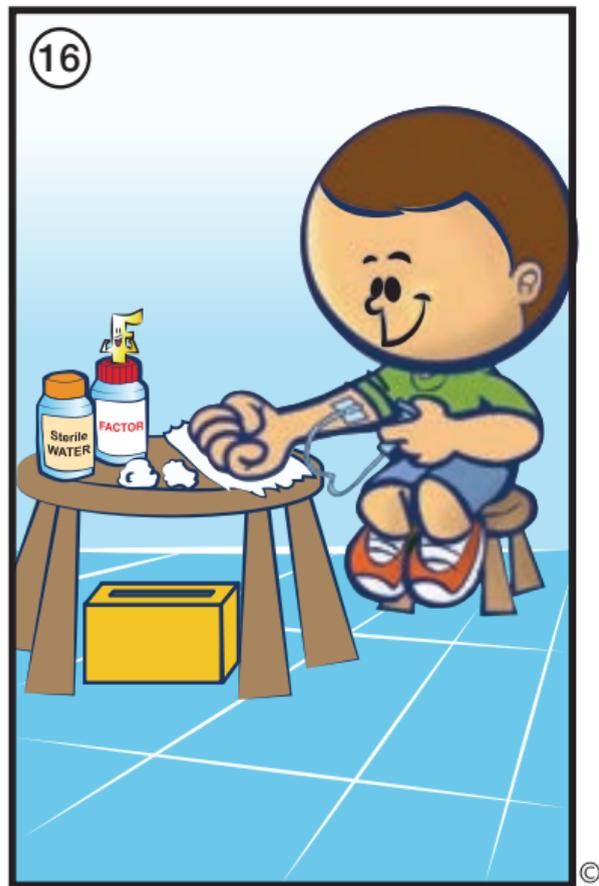
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This boy doesn't need help any more to apply his factor! He already knows how to self-infuse because he learned how to do it correctly at the hemophilia centre.

It is very important that he receive regular prophylaxis treatment! Prophylaxis means infusing factor into his bloodstream several times a week so that he won't have so many bleeds anymore.

He also knows how important it is to give the factor as soon as he hurts himself, because it will help his blood to clot more quickly and avoid damage to his joints.



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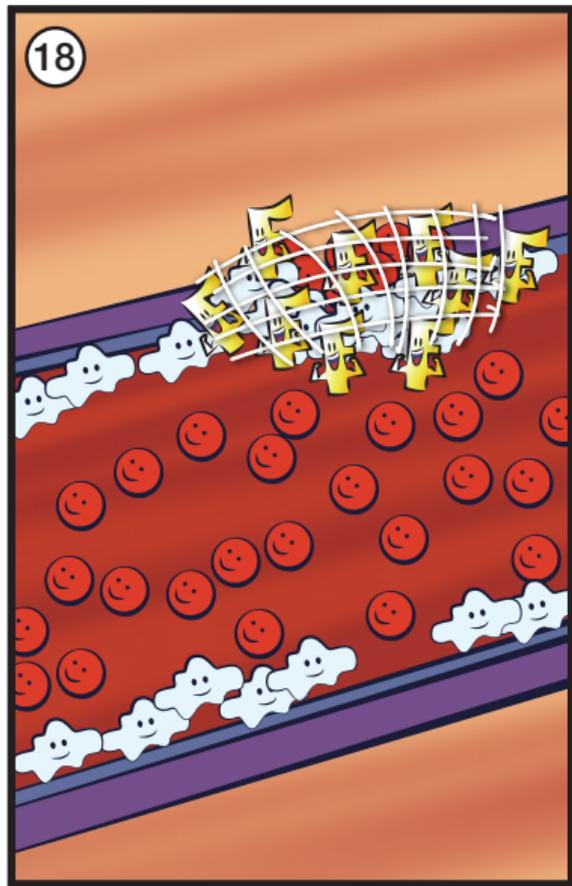
Aha!!! Look at the turtle now!! The factor made him all super-charged and fast! Just like the clotting! Now the bleeding will stop quickly.

People receiving prophylaxis have enough factor in their blood to prevent most bleeds. The super-charged turtle is there to protect them in their different activities!

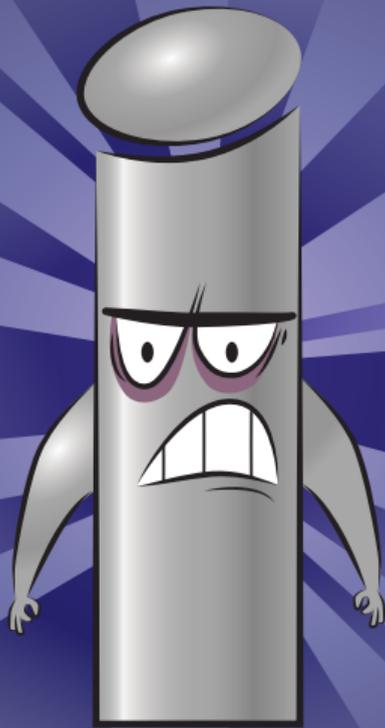
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This is how the fibrin net looks after taking the factor. The factor is helping the formation of a firm and strong fibrin net. It's well made, the blood has stopped coming out and the vein walls are mended!



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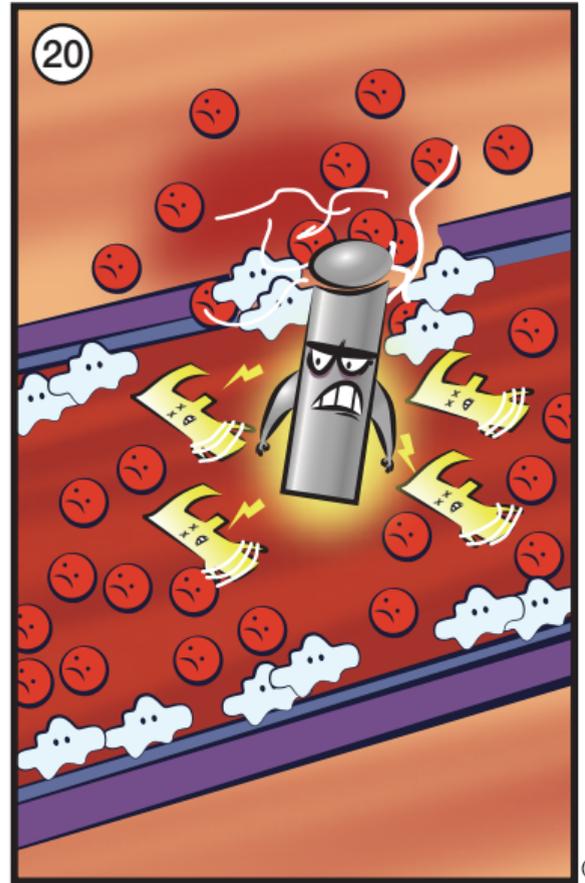


This is I the inhibitor! He seems angry and reactive. In fact, inhibitors can appear in the blood of around 25-30% of children and adults with hemophilia A after infusing factor 8 (FVIII). They can also occur with hemophilia B after infusing factor 9 (FIX) but this does not happen as often. The immune system makes inhibitors as a way of defending the body from something it sees as foreign and dangerous. Inhibitors act against the factor in the blood and cancel out its effect, not allowing it to help stop the bleeding. This is not good because, without the factor, bleeding will not stop! There are treatments available to get rid of inhibitors and to stop bleeds.

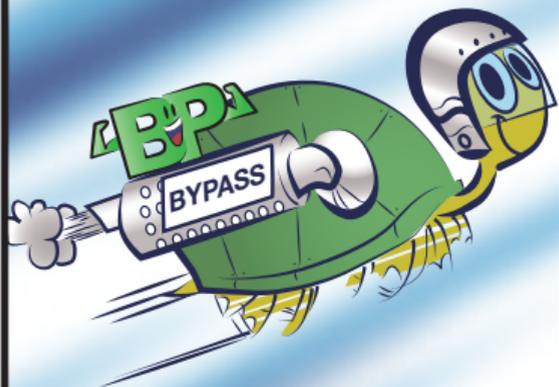
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Here... can you see how the inhibitor is not letting the factor do his job to stop the bleeding? When an inhibitor is present the fibrin net cannot form as it should and the bleeding continues. What should we do?



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How can we make the bleeding stop?

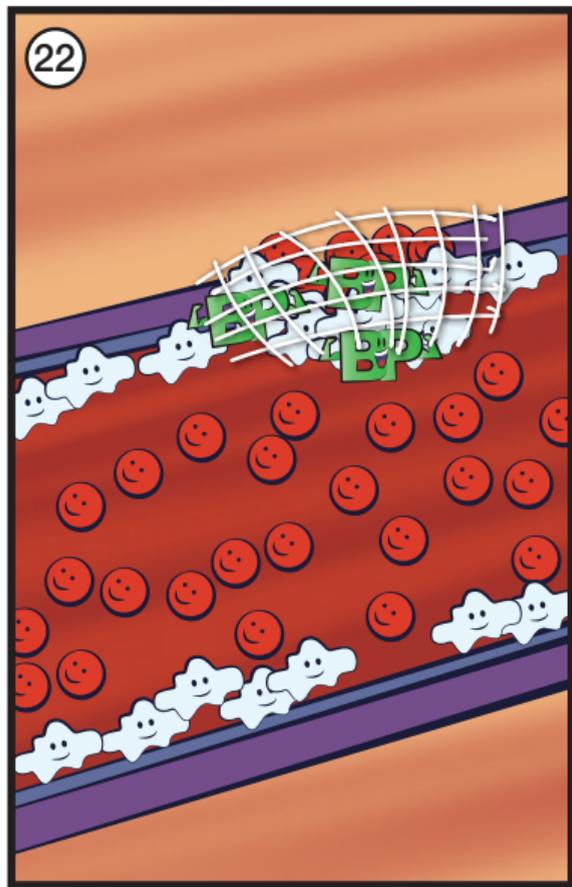
Do you see what Super-charged Turtle is carrying to help?

To stop bleeds when you have inhibitors in the blood, the medicine used is called a bypassing agent. It is different from the factor 8 (FVIII) or factor 9 (FIX) you used before. The immune system does not react against this bypassing agent and the bleeding stops because the clotting process can continue. You can see how the Turtle is going to fix everything by quickly bringing in the agent to stop the bleeding!

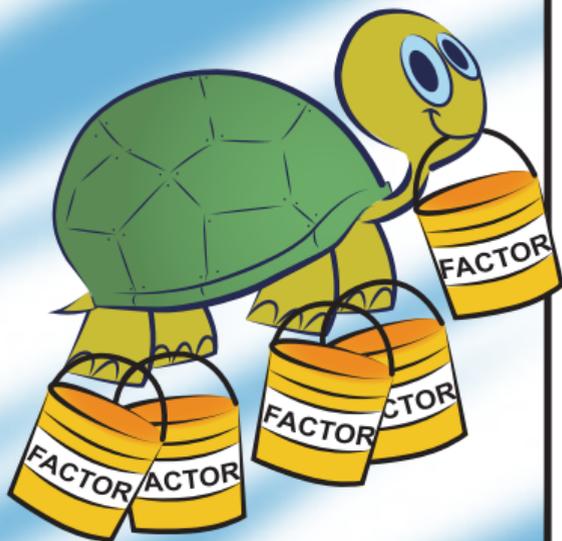
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Done! The bleeding has stopped... and the fibrin net has formed. The bypassing agent helped because the inhibitors cannot attack it. Now, recovery from the bleed is possible. But remember that these bypassing agents do not get rid of inhibitors.



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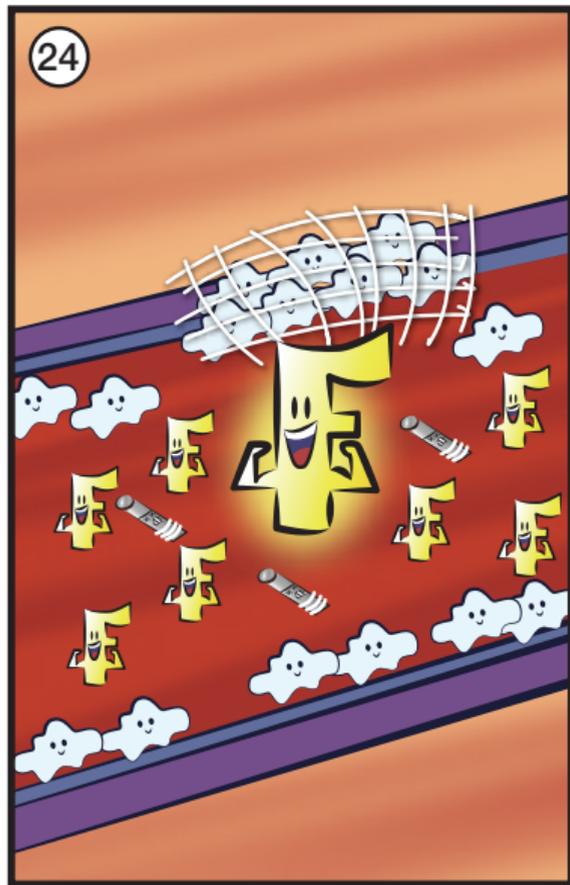
Now, if we want to make inhibitors disappear from the blood, there is a treatment called: immunotolerance induction therapy. It works like this: you receive a large amount of factor everyday to allow the immune system to get used to the factor that it was reacting against – the same factor that you infuse for prophylaxis!

The Turtle is showing that you need a very large amount of factor given many times to make the inhibitors slowly go away!

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As you can see, lots of factor in the blood can make inhibitors go away!! The body gets used to the factor and inhibitors are no longer produced by the immune system.



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To recover completely from a bleed you shouldn't run around too much while the injury is healing.

You have to rest for a few days and let your body get better and then start your physiotherapy! With your physiotherapist, you will learn how to recover your movement and strength and help your body heal itself.

Physiotherapy offers games and exercises that help you get your movement back to normal and make your body get strong again more quickly.

©



In addition to drawing and reading when you are recovering from a bleed, you can also play video games, alone or with your friends. They will bring you joy, allowing you to play your favorite sports while improving skills like memory or strategic thinking. But be careful not to overdo it by sitting for long hours in front of the screen! You need to get back to physical activities so your muscles don't get weak from being inactive.





It's great to learn how to swim!

Swimming strengthens your muscles and helps protect your body's joints.

Swimming and playing in the water are activities that make any kid happy! But you also have to pay attention to a few rules.

Good tips are: Be aware of the slippery floor and move any dangerous objects that can hurt you.



Moving your body and dancing are other good activities to strengthen your muscles and stay flexible! Besides that, they are really fun.

And even more fun when the music is good!





Playing ball? Usually, soccer matches or other contact sports aren't recommended because there's a good chance of falling, bumping into others, and getting hurt!

However, this could change if you're on a prophylaxis program authorized by your hemophilia service and monitored by a specialized professional.

But remember: to play ball, you should always wear sneakers and play on a smooth surface (like grass or sand).



Did you know that hemophilia exists in all the countries in the world and sometimes even girls can have it?

Hemophilia A and B mean that the person's blood clotting doesn't work the way it should. It takes longer for bleeding to stop and this is why the person has to replace the factor that is missing.

Also, bleeding for a long time can be dangerous to your health. That is why it's very important to tell your parents right away whenever you hurt yourself so you can begin treatment as quickly as possible!





Wow! See the boy who doesn't want to take his factor? This is the **RUNNER!** We have to stay away from him! Don't be afraid to take your factor! It's very important to stop bleeding quickly.

At the hemophilia centre, the people who apply the factor have a lot of experience and will always treat you well. And pretty soon you'll be able to learn how to apply it yourself. Won't that be cool?

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