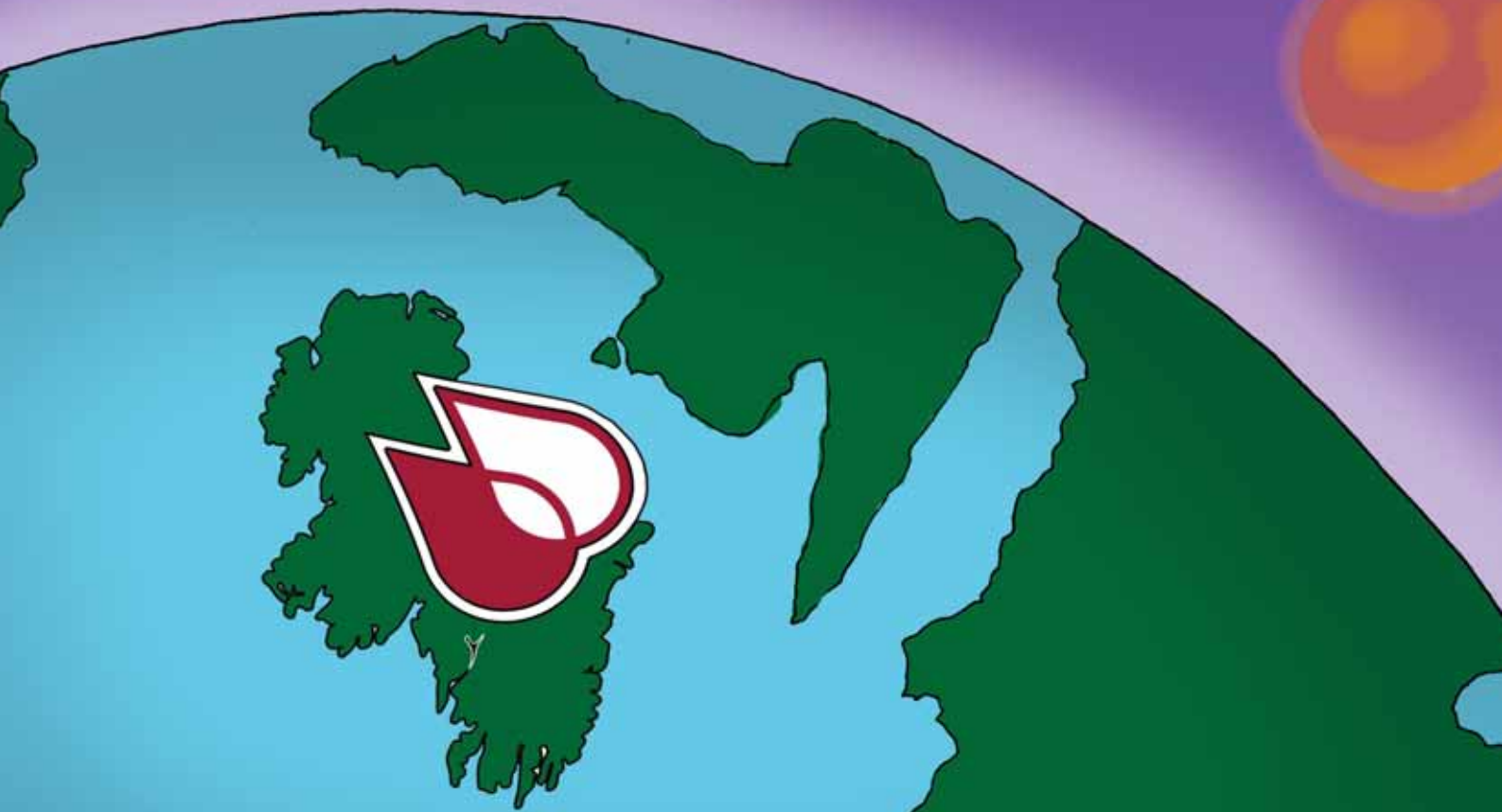


# SIBLING SUPERSTARS!

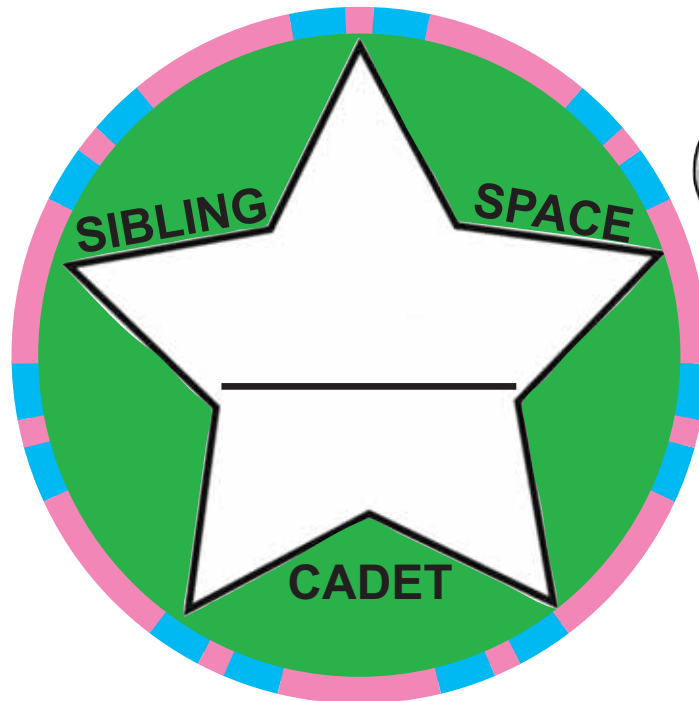


# Introducing...

Greetings Siblings!

Welcome to Sibling Superstars, a workbook and comic for children who have a sibling with haemophilia.

We are Luna and Knox, Sibling Space Cadets. We are here to help you learn about haemophilia, have fun and help you to understand how special you are.



Before we start our adventure we need to sign you up as an official cadet! Write your name on your official badge above and we can begin.

Along our journey we will learn a lot about haemophilia, siblings and more importantly **YOU!** It is not all learning, we have some fun games and activities for you to do along the way. We have put all our fun activities in these colour boxes to help make it easier for you. Remember, you must do the activity before you can move on!

Now let's get started!!

# All about me

Did you know that the Irish Haemophilia Society helps people with haemophilia and their families, which means you!

Just because your sibling has haemophilia and you don't, does not mean we don't want to know about you. We really want to get to know you.

Fill in the spaces below and tell us your story, don't leave anything out.



My name is \_\_\_\_\_ I am \_\_\_\_\_ years old.

My Mam's name is \_\_\_\_\_ and my Dad's name is \_\_\_\_\_.

I have \_\_\_\_\_ brothers and \_\_\_\_\_ sisters. Their names are \_\_\_\_\_

My best friend's name is \_\_\_\_\_.

I have \_\_\_\_\_ pet(s), called \_\_\_\_\_.

I go to \_\_\_\_\_ school.

My class is \_\_\_\_\_ My teacher is \_\_\_\_\_.

My favourite subject is \_\_\_\_\_.

My hobbies are \_\_\_\_\_.

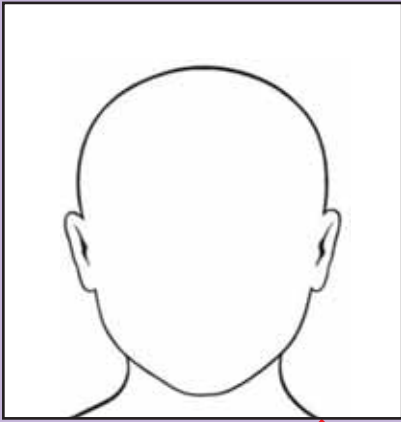
My favourite colour is \_\_\_\_\_.

My favourite food is \_\_\_\_\_.

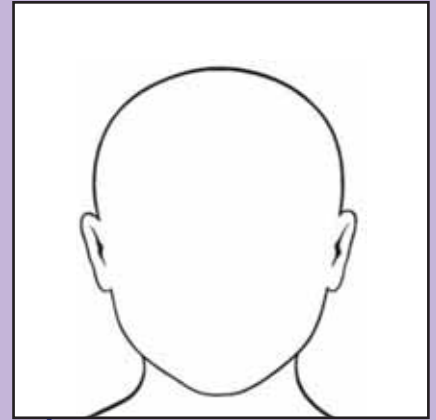
My favourite TV show is \_\_\_\_\_.

# Meet my family

My Mam



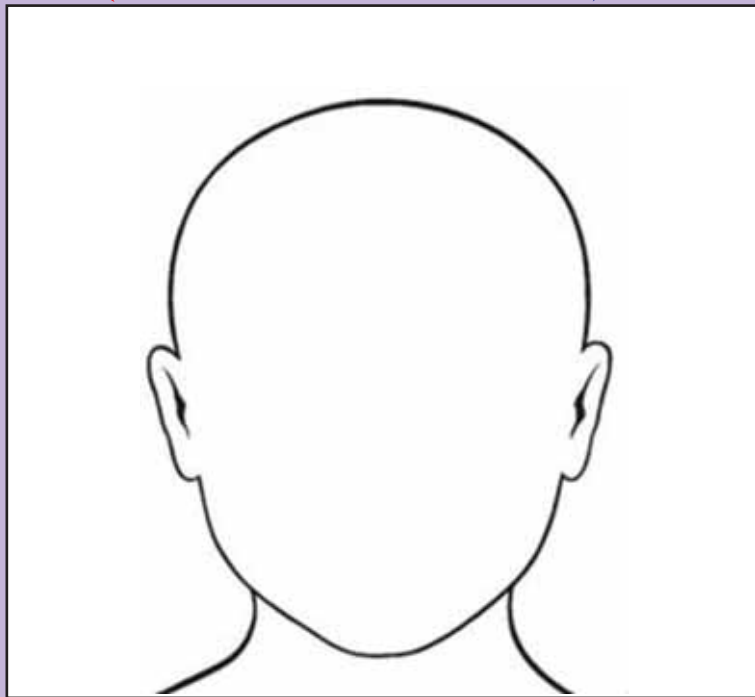
My Dad



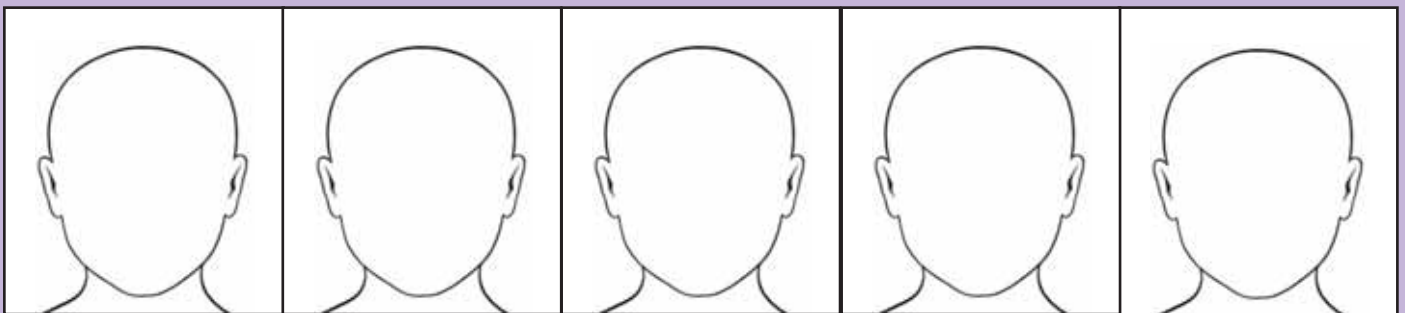
**Time to draw!**  
On the faces below, draw you and your family.

What have you got in common with each member of your family - have you the same colour hair as your Mam or the same colour eyes as your Dad?

ME



My Brothers and Sisters



# Inheritance

Our body is made up of genes (jeans). Genes are the recipe that make you! The ingredients that made you, came from your Mam and Dad. For example, have you got brown hair like your Mam or green eyes like your Dad? These are things you inherited (in-hair-it-did). This means they were passed on to you from someone in your family.

Something that is inherited doesn't have to come from your parents. Sometimes things can skip a generation (jen-or-a-sean). It can skip one person and be passed on to someone else. Has anyone ever said you have your Grandad's eyes, or that you have your Aunt's smile? These different parts of you are all down to genes. So you may have something that your Mam and Dad don't, something that has been in your family before, but you are the first person in a long time to have it.

## Why has my brother got haemophilia and I don't?



Everybody's genes are different, because we are all unique (you-knee-k). This is why your hair might be a different colour from your brother or sister, or why your brother has haemophilia and you don't. When there is a history of haemophilia in a family, there is a 50/50 chance a person will inherit haemophilia. Flip a coin ten times and count how many times you get heads and how many times you get tails. It is a lottery as to what result you get, just like it is a lottery what genes you inherit. However, families share some genes, so you and your family will all have at least one thing in common.

### Still confused?

That's ok a lot of people find it hard to understand. Here's a task for you - find out one thing you have in common with your Mam, your Dad, your Grandmother, your Grandfather and your brother or sister.

### Next let's do a check list.

- |   |                          |                            |                          |
|---|--------------------------|----------------------------|--------------------------|
| Can you roll your tongue?                 | <input type="checkbox"/> | Can anyone in your family? | <input type="checkbox"/> |
| Can you touch your nose with your tongue? | <input type="checkbox"/> | Can anyone in your family? | <input type="checkbox"/> |
| Can you wiggle your ears?                 | <input type="checkbox"/> | Can anyone in your family? | <input type="checkbox"/> |

### My uncle has haemophilia and so does my brother. Is their haemophilia the same?

Yes they will have the same type of haemophilia. Haemophilia is carried through genes, so although it may skip some generations it will never change.

Although their haemophilia may be the same, the way haemophilia affects them may be different. Your uncle may have some mobility (mo-bill-it-tea) problems, maybe he might walk with a limp or find it difficult going up and down steps. However, your brother might play a lot of sports. This is because treatment has changed and has made living with haemophilia easier.

### I understand about inheritance and genes, but what exactly is haemophilia.

Turn the page and let's find out!

# Haemophilia

Haemophilia (He - moe - fill - e - a) is a bleeding disorder. This means the blood of a person with haemophilia works differently to most people, because they are missing a clotting factor.

Our bodies are able to work because the blood in our body carries the food (energy) and oxygen around to all the organs and different parts of the body. We would not survive without blood in our bodies. There are four different parts of the blood:

- 1) Red blood cells which carry the oxygen to give energy to things in our body like our heart and lungs.
- 2) White blood cells which fight anything that is not meant to be in the blood.
- 3) Platelets which help the blood to clot if you get a cut.
- 4) Plasma which is the liquid that carries all of the blood cells around the body.

Blood is made up of 13 factors which work together to form a clot. A clot is a plug which forms when we cut ourselves and stops the blood from leaving our body. When someone is missing a factor it takes longer for a clot to form and so they will bleed for longer.

## Are there different types of haemophilia?

Yes, there are two types of haemophilia known as haemophilia A and B. Haemophilia A is when a person is missing Factor VIII (8) and haemophilia B is when a person is missing Factor IX (9).

Do you know what type of haemophilia is in your family? \_\_\_\_\_

There are also different levels of haemophilia: **mild, moderate and severe.**

A person with mild haemophilia has between 5% to 40% of factor in their blood.



A person with moderate haemophilia has between 1% to 5% of factor in their blood.

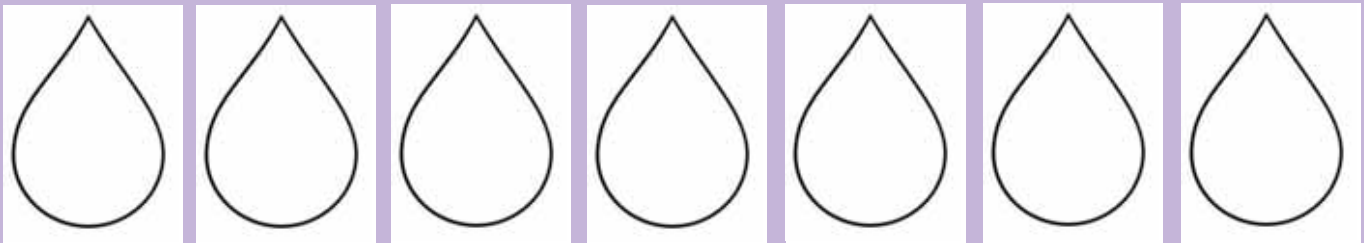


A person with severe haemophilia has less than 1% of factor in their blood.



A person who does not have haemophilia has between 40% to 100% of factor in their blood.

In the first blood drop below, colour in how much factor you have in your blood.



Then ask six other people how much factor they have in their blood and colour in the blood drops. Can you figure out what type of haemophilia each person has?

# Haemophilia

## What happens if you have haemophilia?

When someone has haemophilia they might bleed inside or outside of their body. When you cut your finger and you can see the blood outside of the body this is called external (x - turn - all) bleeding.

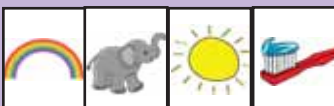
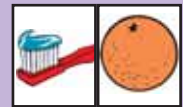
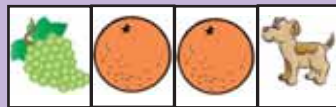
Sometimes you can bleed inside your body too, this is called internal (in - turn - all) bleeding and can happen when someone falls, gets hit or gets a bang. These types of bleeds can happen in the muscles and joints which can be very painful and need to be treated with medicine as soon as possible.

The medicine used to help people with haemophilia is called factor and will increase the amount of factor in their blood. Think of it as an army calling in more soldiers. This treatment is called prophylaxis (pro - fill - axe - is). This treatment helps to prevent bleeds from happening. It means that there is enough factor in the blood to help form a clot so if they hurt themselves, they are less likely to have a bleed. Most of the time the treatment works, but sometimes it doesn't and people need to take more factor to help stop the bleeding.

When a person has a cold they might sneeze or cough, these are signs that they have a cold. People with haemophilia have signs that help them know if they have a bleed. They usually feel pain and the area where the bleed is might swell and become very hot. If a person with haemophilia thinks they have a bleed they should tell an adult straight away so they can help them take their factor.

Sometimes, when a bleed is very bad, your brother or sister might have to go to the hospital to get extra medicine and for some rest. Although you might want to play with your brother, it is very important to let him rest when he has a bleed because if he doesn't the bleed could get worse and then he might have to stay in hospital and nobody wants that.

Using the code breaker on page 17 can you crack the secret code below?



# Haemophilia and Me

When someone in your family has haemophilia, most of the time they are just like you, you might even forget they have haemophilia!! Sometimes, they might get a bleed and things will change a little bit at home. Your sibling might be a bit sad because they have a bad pain. Your parents might be giving your sibling lots of attention and that might make you feel annoyed or left out.

It is important to remember that your sibling just needs some rest and time to feel better and your parents have to look after your sibling just like they do for you when you are sick!!

Before you know it your sibling will be feeling better again and everything will be the same as it was before!

In the meantime why not think of things that you can do when your sibling has a bleed.....

My favourite game to play is Guess Who. Knox prefers to play on his computer.



If your sibling has to rest and lie down maybe you two could play a board game. What are your favourite board games? Maybe you could watch a movie, have some popcorn and pretend you are in the cinema!

Luna and Knox both like different games, but they take it in turns to play each others game so that everyone has fun. It is important to share - this is something you and your sibling must do.

Do you know what your sibling's favourite game is? If not, go and find out!

I love playing computer games, but Luna doesn't.

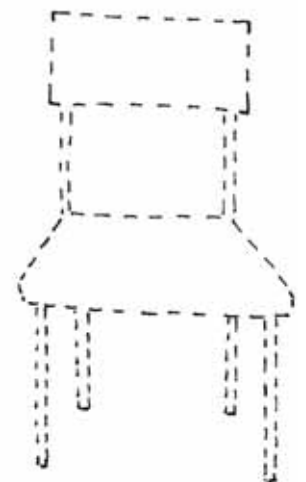


Sometimes your sibling might have to go to hospital if they have a bad bleed. It might be nice to go and visit them and maybe bring a game the two of you could play.

Even though they don't like being in hospital it will cheer them up to have some fun with you!!

Being in hospital can be lonely. Everyone loves a visitor.

Draw someone visiting Neil and don't forget to colour in the picture!











SOMETIMES THERE CAN BE A LOT GOING ON AND WE CAN FORGET THINGS. BUT IT DOESN'T MEAN THAT WE DON'T CARE.

SO THEY DO LOVE ME?

THEY KNOW? WHY HAVEN'T THEY SAID ANYTHING TO ME?

OF COURSE THEY DO EMMA, DON'T EVER FORGET THAT. SOMETIMES HAEMOPHILIA MIGHT MEAN THEY CAN'T BE THERE TO WATCH YOU. BUT THEY ARE ALWAYS THINKING OF YOU.



LET'S GO TO OUR NEXT STOP!



THAT'S MY BROTHER NEIL!

HE LOOKS BORED!



ARE YOU OK NEIL?

I JUST WISH I COULD HAVE GONE TO THE PARTY WITH SEAN.

SEAN DIDN'T GO TO THE PARTY. HE IS OUTSIDE WAITING ON ME.

WHY DIDN'T HE GO? I HOPE IT WASN'T BECAUSE OF ME! CAN I SEE HIM?



YOU HAVE AN OPERATION TOMORROW, YOU HAVE TO STAY IN BED.

CAN HE COME IN AND SEE ME? I'M REALLY BORED!

NO HE CAN'T, YOU NEED TO REST. I'M GOING TO BRING HIM HOME AND YOUR DAD WILL BE IN TO SEE YOU LATER, OK?



PLEASE STAY, I DON'T WANT TO BE HERE ON MY OWN!

IT'S ONLY FOR A LITTLE WHILE. YOU BE BRAVE, OK?



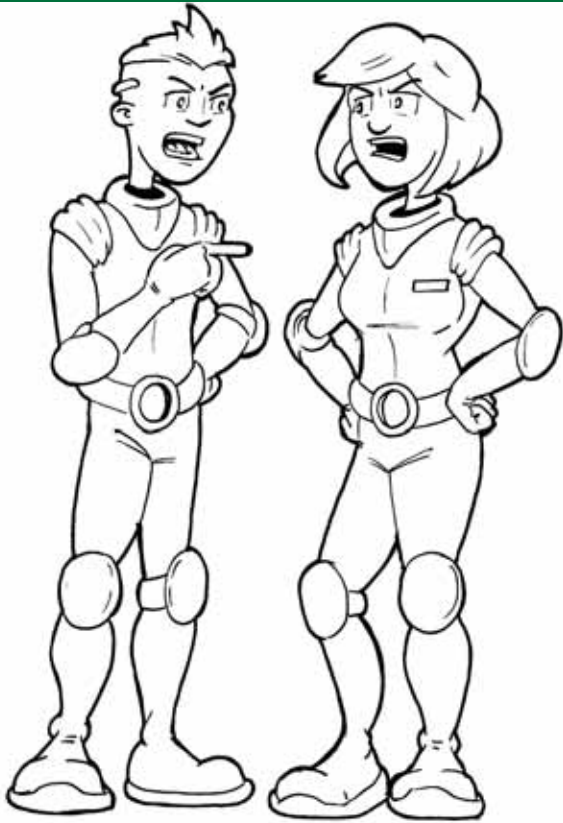
I WISH I COULD GO AND TELL HIM IT'S NOT HIS FAULT. HE LOOKS SO LONELY.

HOSPITAL CAN BE A LONELY PLACE. I KNOW YOU DON'T LIKE COMING TO VISIT BUT IF YOU DIDN'T, HE WOULD BE ON HIS OWN.

WE'D BETTER GET YOU BACK BEFORE YOUR PARENTS COME LOOKING FOR YOU.



# Haemophilia and my Sibling



## Do you ever fight with your sibling?

At some stage everyone has a fight or is annoyed with their brother or sister, it can be for lots of different reasons. What kind of things do you fight about with your sibling?

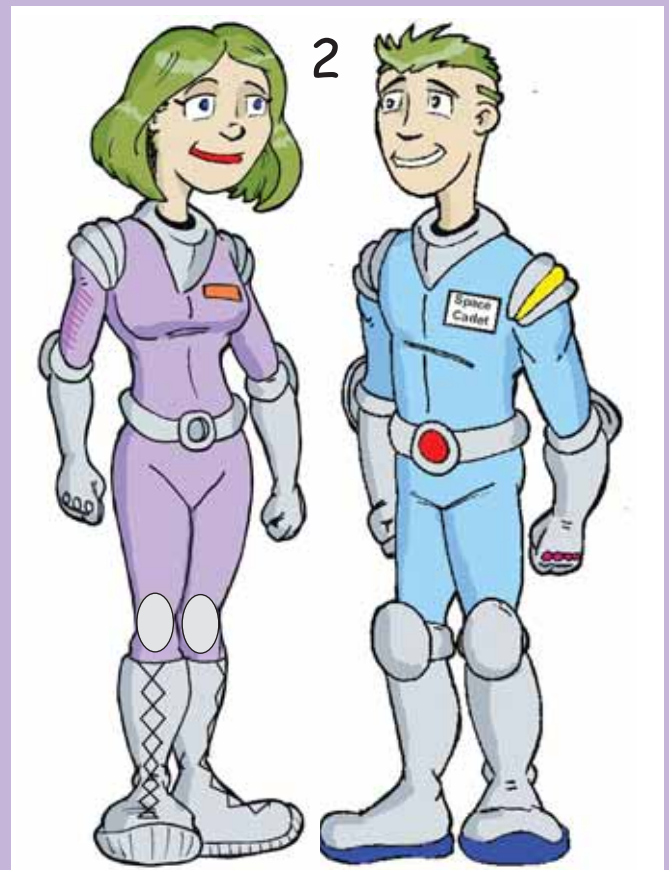
When you are angry with someone, telling them how you feel can be hard. Here is a fun idea to help you and your sibling understand each other so you can keep having lots of fun together. When you have had a fight with your brother or sister why don't you write down on a little piece of paper what made you angry or sad and put it in a bottle, get them to do the same thing. At the end of the week – ask your parents to take the notes out of the bottle so you and your sibling can talk about how you feel!!

Do you notice anything about both of your notes?

We hope this helps you to become the best of friends again!

Everyone is unique. Although you and your sibling may be alike, you are different.

Can you spot the sixteen differences between the pictures below?

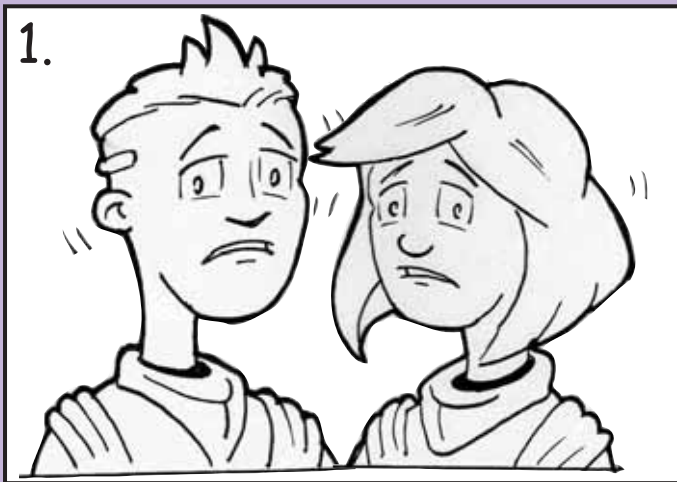
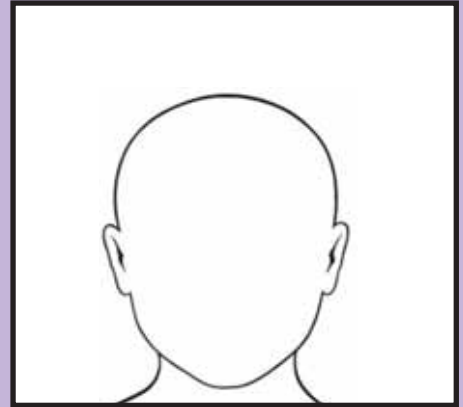


# Feelings

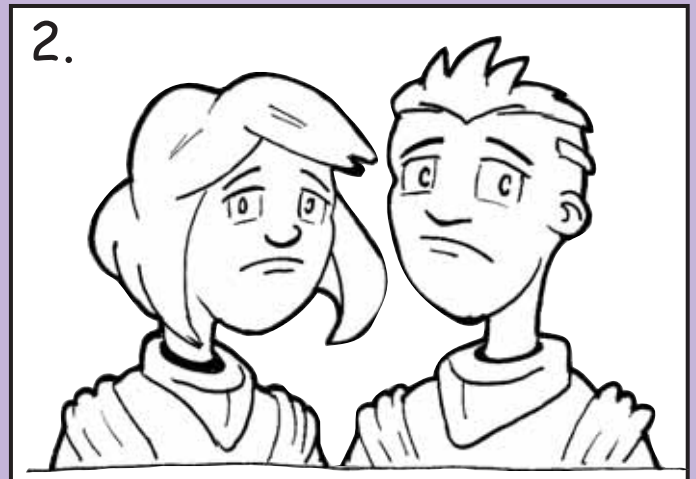
Sometimes we show how we feel on our face. When we are happy we smile. When we are angry we frown. When we are sad we cry.

In the box on the right, draw how you feel right now!

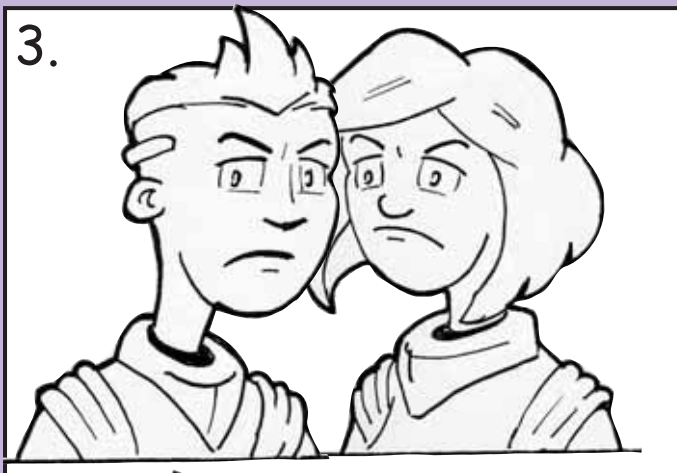
Can you identify the different emotions that Knox and Luna are feeling? Don't forget to colour them in!



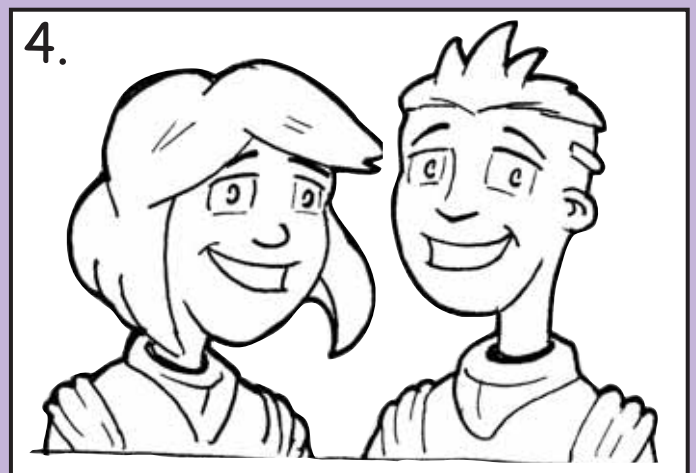
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There are times when we don't show how we feel, so it is hard for others to know how we feel. If we can't show people how we feel, we must tell them!

Feelings Answers: 1) Scared, 2) Sad, 3) Angry, 4) Happy.

# Feelings

As a sibling there are times when we feel jealous and envy our brother or sister. When your sibling has a bleeding disorder you might think that your parents spend more time with your sibling or that he or she gets more attention than you. This can also make you feel angry.

If your sibling has a bad bleed and has to spend time in hospital you might feel scared because you don't know how long it will take for them to feel better. You can also feel sad because you miss them.

Do you ever feel angry at yourself because you feel something bad towards your sibling? There are lots of different feelings. Any feeling you have, good or bad, shows how much you love your sibling and your family. Your family love you too and want you to share your feelings.

If you are feeling sad, scared, happy or angry it is important to talk to your parents. Telling someone how you feel can help you feel better. How? Because other people feel the same as you. You are never alone.

Talking to someone means they understand you, when they understand you they can help you. Sometimes it can be a hug that helps. Other times it might take longer, but there is always time for you. Trust us, talking to someone will help you feel better.



When your parents and sibling are talking about haemophilia you might feel left out because you don't know some of the words they are using. We have five words below, can you match them with their meaning? Ask your parents and sibling to help you and learn together!

- |                  |  |
|------------------|--|
| 1. R.I.C.E.      | A. Exercises to help build strong muscles. It is important for people with haemophilia to do these exercises after a bleed.          |
| 2. Port-a-cath   | B. A strap that is tied around the arm to make your veins bigger.  |
| 3. Infusion      | C. Rest, Ice, Compression and Elevation - this is what people with a bleeding disorder should do when they have a bleed.             |
| 4. Tourniquet    | D. Another word for injection. When treatment is given to a person using a syringe.  |
| 5. Physiotherapy | E. Also known as a Freddie this is a device placed under the skin in people who haven't got strong veins to help them get treatment. |

# Games

Space Cadets, we have learned a lot now it's time for some fun.

Use your code breaking and problem solving skills and solve the puzzles and games we have set you.

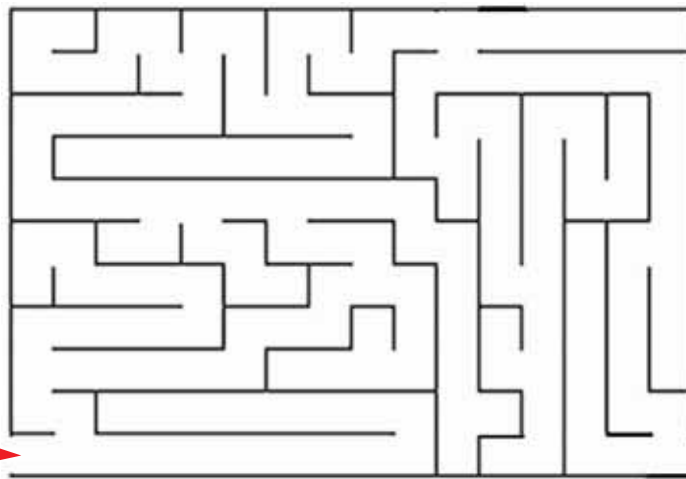
Have fun!



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

Can you find the following fifteen words in the wordsearch?

- |      |       |         |           |                   |
|------|-------|---------|-----------|-------------------|
| LUNA | GENES | SISTER  | INHERITED | SUPERSTARS        |
| IHS  | BLEED | BROTHER | HOSPITAL  | BLEEDING DISORDER |
| CLOT | KNOX  | FACTOR  | FEELINGS  | HAEMOPHILIA       |

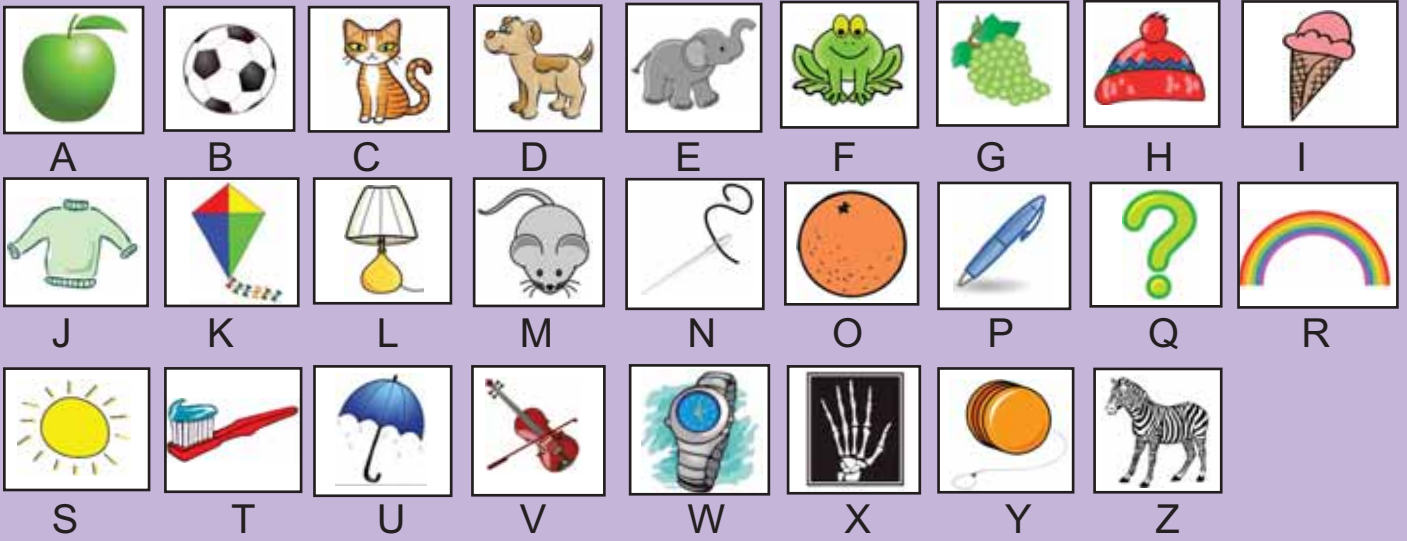


Can you help Luna & Knox find their spaceship?

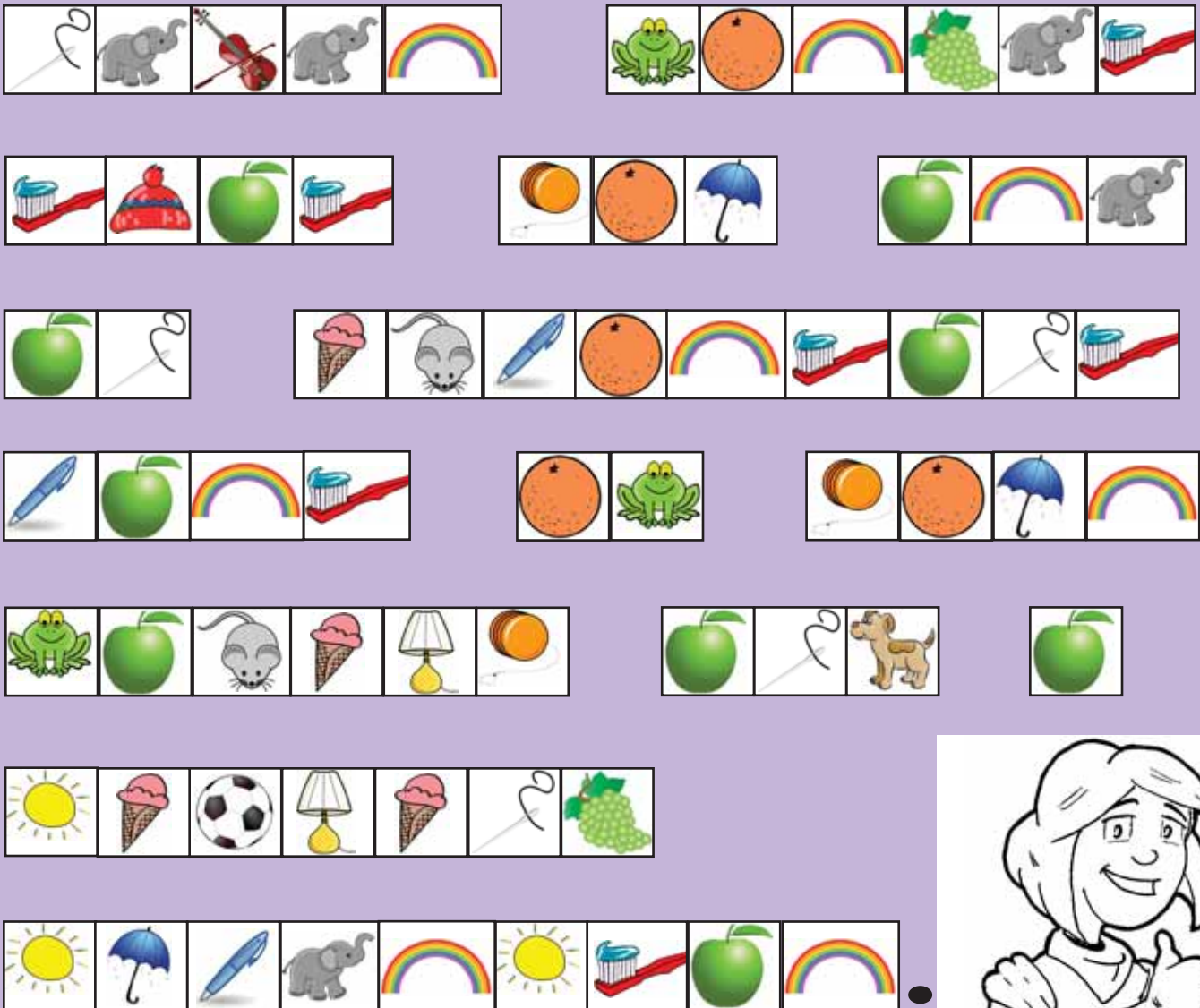




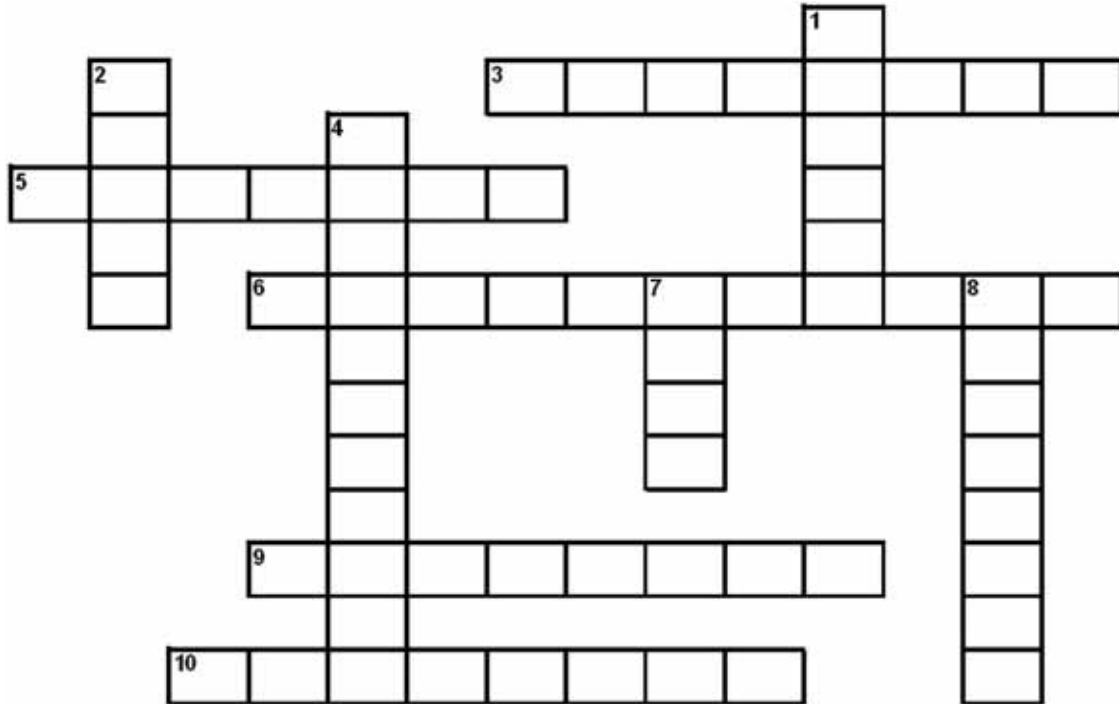
# Games



Using the code breaker above can you crack the secret code below?



# Games



## Down:

1. Your sibling should also be your \_\_\_\_\_ (6)
2. Things we inherit from our parents are called \_\_\_\_\_ (5)
4. The regular treatment for haemophilia is called \_\_\_\_\_ (11)
7. A person with haemophilia takes factor to help their blood \_\_\_\_\_ (4)
8. How many factors are there in blood? \_\_\_\_\_ (8)

## Across:

3. When a person bleeds on the inside it is called an \_\_\_\_\_ bleed (8)
5. Hair colour and eye colour are two examples of things we \_\_\_\_\_ from our parents (7)
6. Luna and Knox are Sibling \_\_\_\_\_ / \_\_\_\_\_ (5,6)
9. When a person bleeds on the outside it is called an \_\_\_\_\_ bleed (8)
10. When a person is very sick, they may have to spend time in \_\_\_\_\_ (8)

## Answers:

**Codeword page 7:** Watching a movie is a good way to rest and have fun at the same time.

**Spot the difference page 13:** Knox: Mouth, Badge, Colour of Uniform, Belt, Bottom of Boots, Glove, Shoulder, Hair Colour.

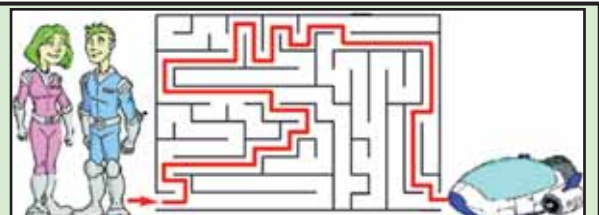
Luna: Mouth, Eye Colour, Right Arm, Colour of Uniform, Knee Pads, Laces on boots, Badge, Hair Colour.

**Word Match page 15:** 1 = C, 2 = E, 3 = D, 4 = B, 5 = A.

**Codeword page 17:** Never forget that you an important part of your family and a sibling superstar.

**Crossword page 18:** Down: 1) Friend, 2) Genes, 4) Prophylaxis, 7) Clot, 8) Thirteen

Across: 3) Internal, 5) Inherit, 6) Space Cadets, 9) External, 10) Hospital



Page 16: Maze and Wordsearch Solutions.



# Your Star Status

Being a sibling is an important job that carries responsibilities.



We want to reward you for being such a great sibling. Colour in all the stars that apply to you. When you have all the stars complete and you reach the yellow star contact the I.H.S. for a special prize!



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