

Sam Hurts Himself

A Book about Bleeding Disorders



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This book belongs to:

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Sam is lying in bed wide awake and can't sleep.

He's going to start at a new school tomorrow. It's both exciting and scary. Sam is new and doesn't know anyone in his class.

"The other kids probably have butterflies in their tummies too," says Mum at the breakfast table.

But Sam is the most nervous of them all. He will have to tell them that he has haemophilia. Mum has already spoken to Sam's teacher and the school nurse about it, but today it will be Sam's turn to tell the class himself.

"Be careful at playtime," says Dad. He and Mum are worried that Sam will fall and hurt himself.

Bleeding disorder is a general term covering different diseases where a person's blood doesn't coagulate (clot) normally. A person with a bleeding disorder bleeds more easily than others and can also bleed for longer than a healthy person. They can also start bleeding for no reason at all.

There are three levels of haemophilia: mild, moderate and severe. "Moderate" is another word for medium. Haemophilia is a hereditary disease, which means that a person is born with it. It's not contagious.

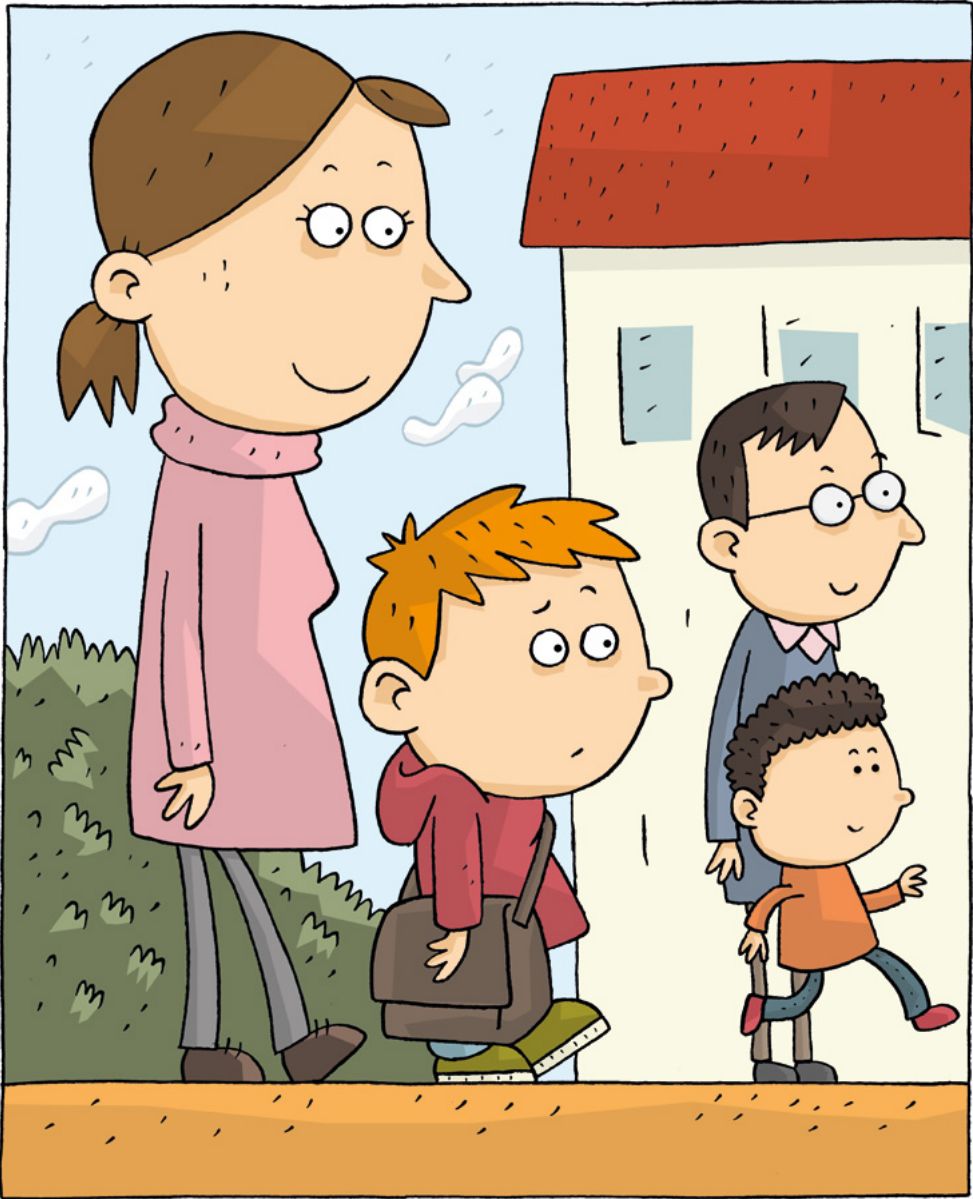
Mum goes with Sam to school.

There are lots of grown-ups standing in the playground talking to one another. There are children there too. Some of them are playing together.

“Don’t forget to tell them that you have haemophilia,” says Mum. “I won’t,” Sam replies.

She gives him a hug before she leaves.

It’s good for your classmates, teacher and the school nurse to know about your condition. You should also tell your PE teacher, crafts teacher and the staff at your leisure centre. That way, they will know what they should do if you hurt yourself and start to bleed.



In the classroom, you can choose your own desk. Sam takes a desk by the window. He can see lots of dogs running around outside.

“It’s a doggy daycare,” says the girl sitting next to Sam. Sam asks her what happens at a doggy daycare. “I think they play all day,” she replies.

The teacher welcomes the pupils to the class. His name is Emre. He talks for a while about summer holidays, the schedule and school dinners and then he says: “Most of you know each other already, but since some pupils are new, let’s introduce ourselves to one another”.

Sam looks around the classroom. He wonders which kids are already friends.







Emre asks them all to sit in a circle.

They have to write their names on a sign and then hold it up and tell the class something about themselves. Sam knows what he's going to say. At least, he knows what he's promised Mum he will tell the class.

“My name is Melker and I have three sisters,” says one boy.

“My name is Alva and I went to Italy during the summer holidays,” says a girl.

“My name is Ali and I have a new skateboard,” says another boy.

“My name is Saga and I like dogs,” says the girl who sat at the desk next to Sam's. Then she tells the class that she's got a dachshund called Gunnar.

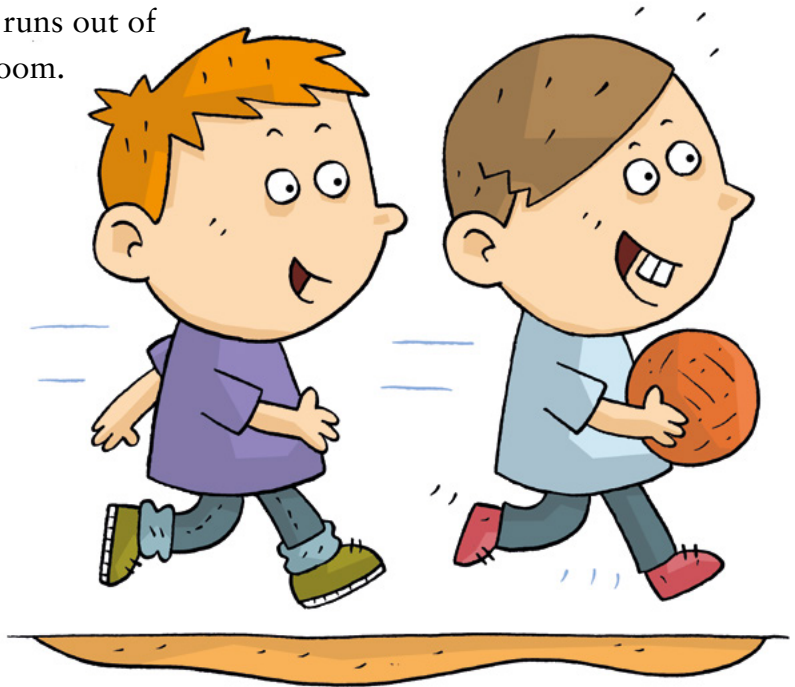
What an unusual name for a dog, thinks Sam. Sam's grandpa is also called Gunnar.

Now it's Sam's turn to introduce himself. He is feeling a bit shy. Everyone in the circle is looking at him. Sam is going to tell them his name and explain that he has haemophilia. He takes a deep breath.

"My name is Sam and I..." he starts to say. Just then, the bell for playtime rings.

"We'll have to continue the introductions after playtime," says Emre.

Everyone runs out of the classroom.



The school's playground has a football field, swings, a slide and a climbing frame.

This playground is much better than the one at my old school, thinks Sam. He plays with Ali, Alva and Melker. The three new friends have fun together.





Suddenly, when he is high up on the climbing frame, Sam loses his grip and falls.

“Help!” he cries as he falls.

Before he hits the ground, he remembers what Dad said to him at breakfast this morning: “Be careful!”.

Now Sam will *have* to tell the others about his disease.



Sam is lying on the ground. He looks up and sees Saga standing over him.

“I’ve got a bleeding disorder,” says Sam. He points to his leg. There is a graze on his knee. It hurts and is bleeding a bit too.

Saga tells Sam to lie still. “Go and fetch something freezing cold from the cafeteria,” she tells Ali. “Ask the school nurse for some compresses,” she calls to Alva.

Huh? How does Saga know all this? Sam is very surprised.





A few minutes later, Ali comes back with a bag of frozen peas.

Then Alva comes running. She has the school nurse with her. Sam is still lying on the ground.

The nurse wraps the bag of peas in a towel. First, she asks Ali to hold it against Sam's knee for a long time.

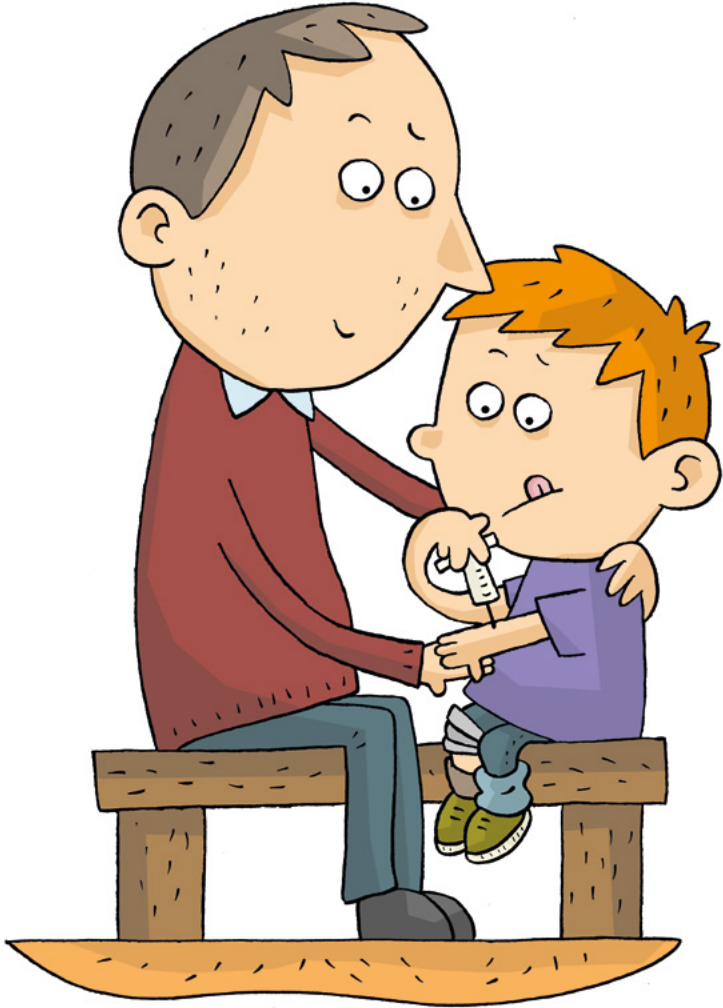
Then she wraps an elastic bandage around Sam's knee. She pulls it quite tight.

Next, she lifts Sam's leg up high in the air with one hand. In her other hand is a mobile phone. The nurse calls Sam's dad.

If you have a bleeding disorder and hurt yourself, either you or a grown-up should call your parents. Your parents know what needs to be done and can come to your school, if necessary. The school nurse can also help.

If you hurt yourself badly, such as an injury to your head, throat, or stomach, or if the bleeding doesn't stop, a grown-up must quickly call the local coagulation unit (*koagulationsmottagningen*). They are experts on bleeding disorders. You might also need to call the emergency number, 112.





After a while, Dad arrives. He has Sam's medicine with him. The medicine, when injected into his body, helps stop the bleeding. In other words, it makes Sam's blood work like other people's blood.

Sam usually takes his medicine every second morning, but now, when he has hurt himself so badly, he needs extra medicine. Otherwise, his injury might get worse.

Dad injects the medicine into Sam's arm. Sam helps him.

When you're a child, your parents will usually give you your treatment. When you're older, however, you will need to learn to do this yourself. The nurses at your local coagulation unit will teach you how.

Dad has brought some crutches with him too. Sam hasn't needed those since he fell off his bicycle last year. After that, he had to use the crutches for three days.

Sam starts to cry. He has to go home now, even though he's only been at school for a few hours!

"See you tomorrow!" Melker calls after him, but Sam is too sad to reply.

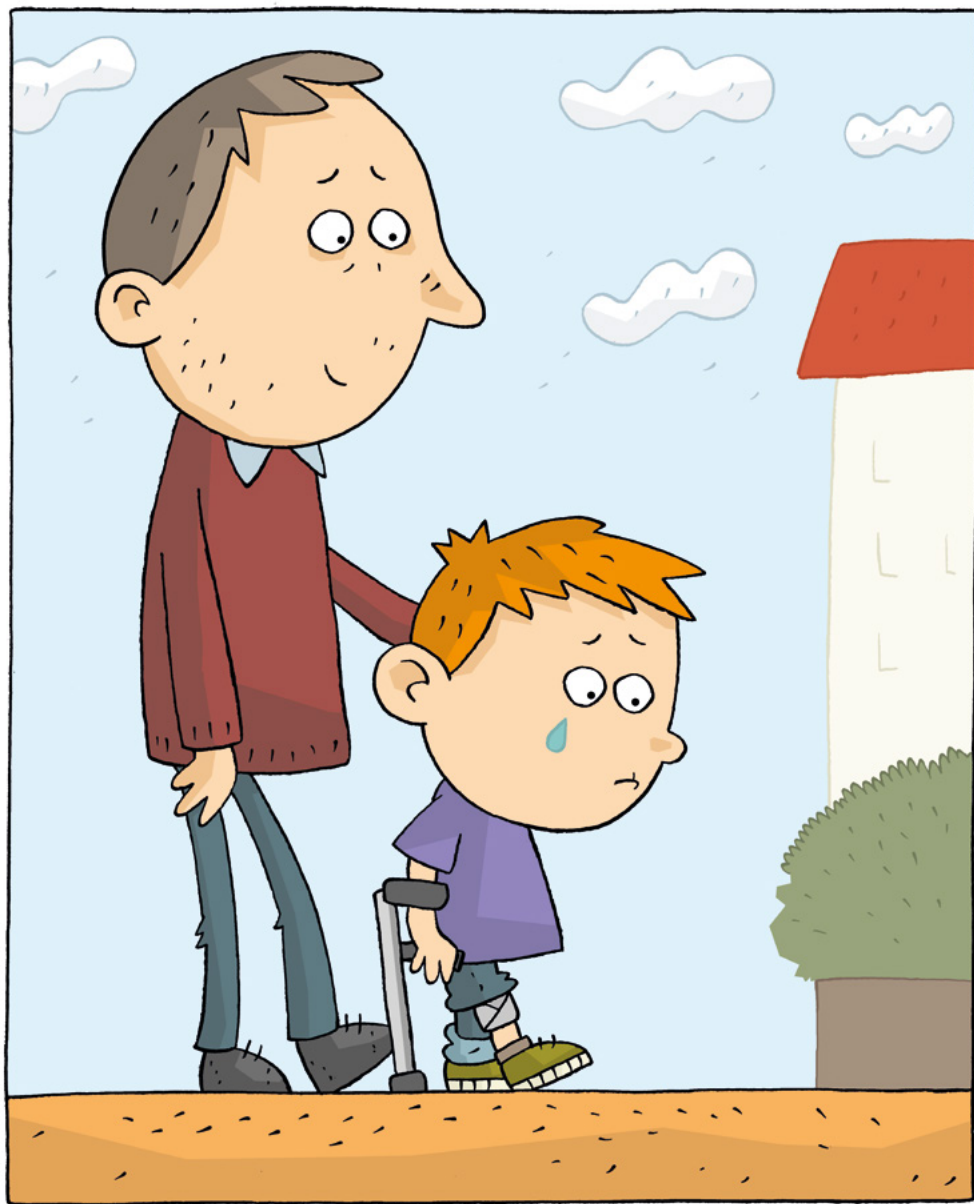


Dad thinks it's best that Sam takes it easy for the rest of the day. Boring, Sam thinks. It had been such fun to start school! At least until he hurt himself, that is.

He wonders what his new friends are getting up to at school. Perhaps they're drawing and painting, or doing sums.

Injuries don't always show on the outside. You can bleed *inside* your body too. That's why you need to tell a grown-up when you hurt yourself. It's important to protect yourself too. Just like other kids, you must always remember to wear a helmet when you ride a bike, go skiing, or skateboarding. You might also need to take extra medicine if you hurt yourself.

If you have hurt yourself and are bleeding, it is important to rest. During that time, you might sometimes need crutches, a wheelchair, or a walking frame so that the part of your body that is injured can rest and heal.

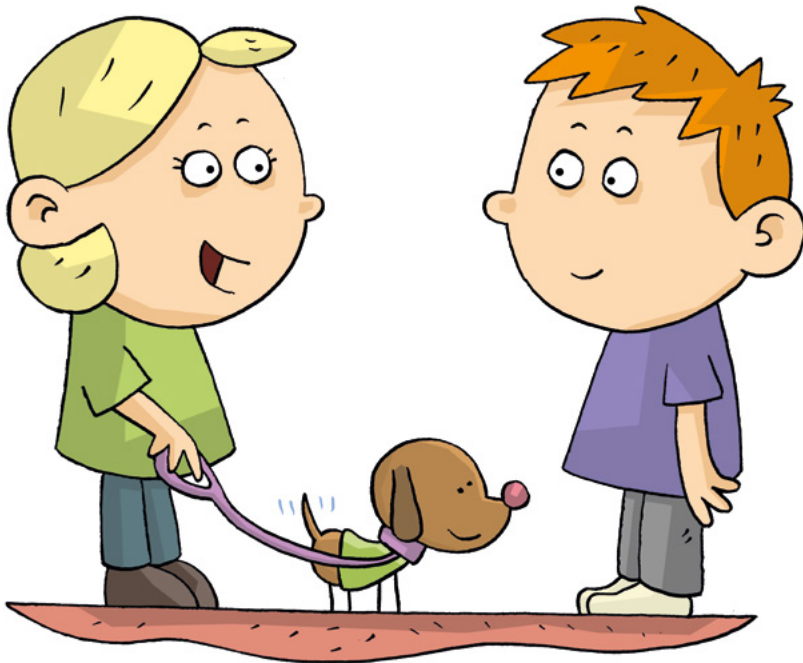


Sam looks at the clock in the kitchen. It's 5 past 5.
Dad is making tacos for dinner, Sam's favourite. Suddenly,
the doorbell rings.

"I'll get it," says Dad.

It's Saga! She has her dog Gunnar with her too. Gunnar is
wearing a purple collar and a green sweater.

"Can we come in?" Saga calls from the hallway.



“Of course!” Sam replies. Saga’s visit makes Sam feel happy again.

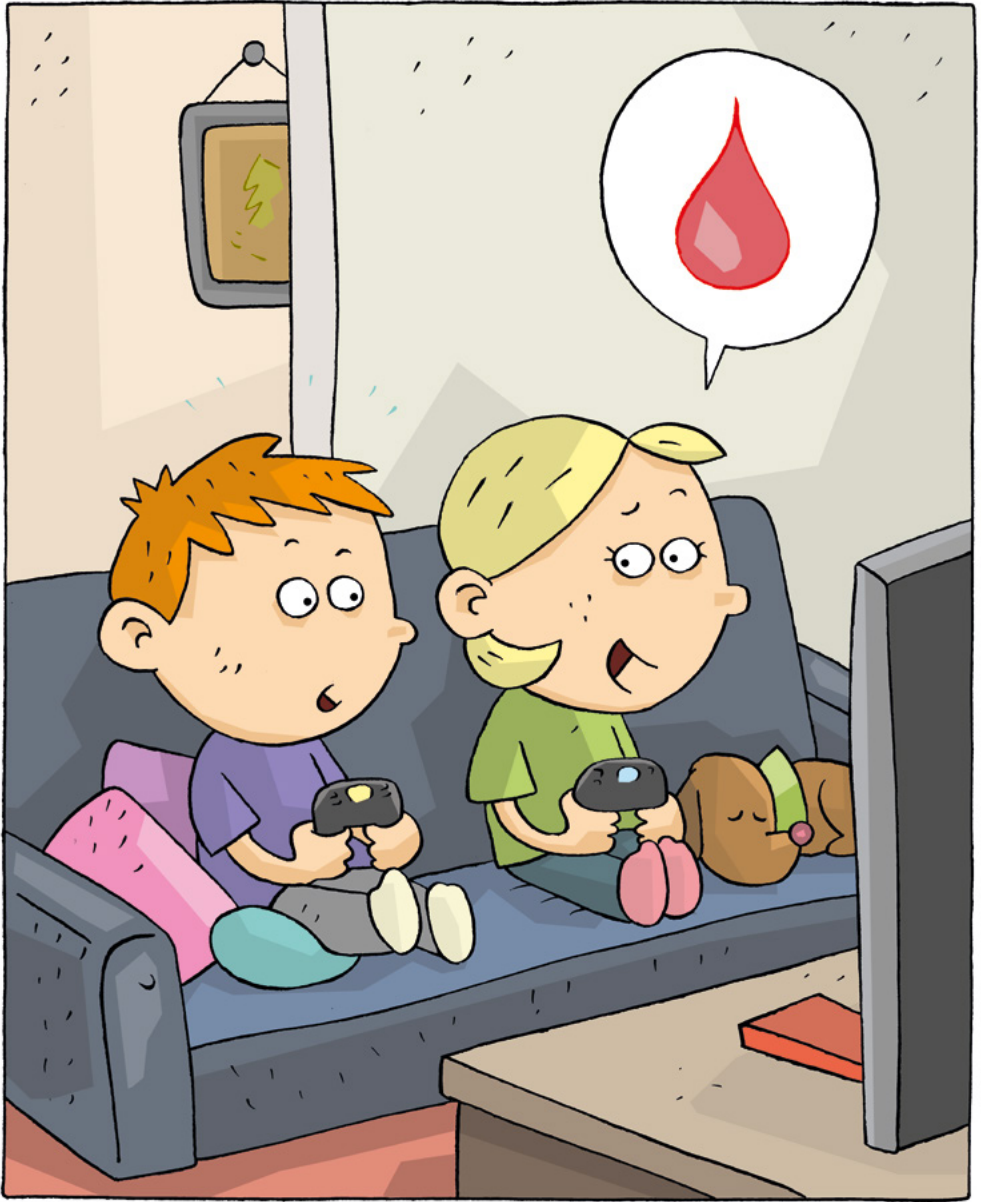
Saga explains that she lives in the same building. She saw when Sam’s family moved into their new apartment a few weeks ago.

They eat tacos together. Sam tells Saga about his haemophilia.

“I was two when they discovered that I had the disease,” he says. He explains that he has to visit a special clinic at the hospital twice a year. It’s called the Coagulation Unit. There they check that his medicine is working as it should, so that the bleeding will stop if he hurts himself.

While he is talking, it seems like Saga has something on her mind, but Sam forgets to ask her what she’s thinking. He’s too busy telling his own story.

There are many different types of bleeding disorders. Two common types are haemophilia A and B, which almost only affect boys. These disorders make it more difficult for a person’s blood to coagulate, which means that it doesn’t clot as well as it does in other people. People with haemophilia A have less or no *clotting factor 8* in their blood. People with haemophilia B have less or no *clotting factor 9* in their blood. Both diseases make it difficult to stop bleeding. The medicine that people with more severe forms of bleeding disorder take helps them to stop bleeding. Sam, the main character in this story, suffers from severe haemophilia, so his blood doesn’t coagulate at all. That’s why he needs medicine.



After dinner, Sam and Saga sit on the couch and play video games together. Sam's knee is still swollen and tender. Gunnar lies snoring beside Saga.

Suddenly, Saga says: "Do you want to know a secret, Sam?". Sam is all ears.

"I've got a bleeding disorder too," she says.

"What?!" Sam bursts out. He didn't think girls could have bleeding disorders.

"My bleeding disorder is called von Willebrand disease. Dogs can have it too," Saga explains.

"Has Gunnar got a bleeding disorder too?" Sam asks.

"No," Saga replies. "But dogs can have the disease just like humans. In that case, they also have to take medicine," she adds.

Von Willebrand disease is the most common type of bleeding disorder. It can affect both boys and girls. Just like with other bleeding disorders, von Willebrand disease makes a person bleed more easily and may mean that they need to take medicine. It can be either mild, moderate, or severe. The disease is named after the Finnish doctor who discovered it. His name was Erik von Willebrand.

Around 1 in every 100 people has von Willebrand disease. One person in every 10,000 has haemophilia A or B.

Saga explains that her bleeding disorder means that she often gets nosebleeds and that she bruises easily, just like Sam.

Now Sam understands how Saga knew what to do when someone gets hurt. They talk about bleeding disorders for a long time. Saga tells Sam a lot of things he didn't know before. Dad comes in holding an ice cream cone for each of them.

“I haven't told the class yet either,” says Saga just before she and Gunnar go home. Sam and Saga decide to tell the class together tomorrow.

“It'll probably be easier when there are two of us,” says Saga. Sam agrees.



When bedtime comes around, Sam isn't so sad any more. He's made a new friend who lives in the same building and tomorrow he'll get to see Ali, Alva and Melker again!



This book has been produced by the
Swedish Hemophilia Society and CSL Behring
and has been reviewed for medical accuracy
by the Coagulation Centre at
Sahlgrenska University Hospital.

You are welcome to contact the
Swedish Hemophilia Society via www.fbis.se
if you would like more information or want to
meet others with bleeding disorders.

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A Book about Bleeding Disorders

Sam is about to start at a new school and is a bit nervous. He is going to tell everyone that he has a bleeding disorder.

I'll tell them later, he thinks as the bell rings for playtime. Then, when he is high up on the climbing frame, Sam suddenly loses his grip and falls. "Help!" he cries as he falls. Before he hits the ground, he remembers what his Dad said to him at breakfast this morning: "Be careful!". Now he will have to tell the others about his disease.

Sam Hurts Himself is a story about starting at a new school and about friends and secrets. The book takes us along on a day in the life of Sam, who has haemophilia, and of Saga, who has von Willebrand disease.

In his work as an author, Nicolas Jacquemot has written a number of books for young people about how the body works. Henrik Lange is a well-known illustrator of children's books.

