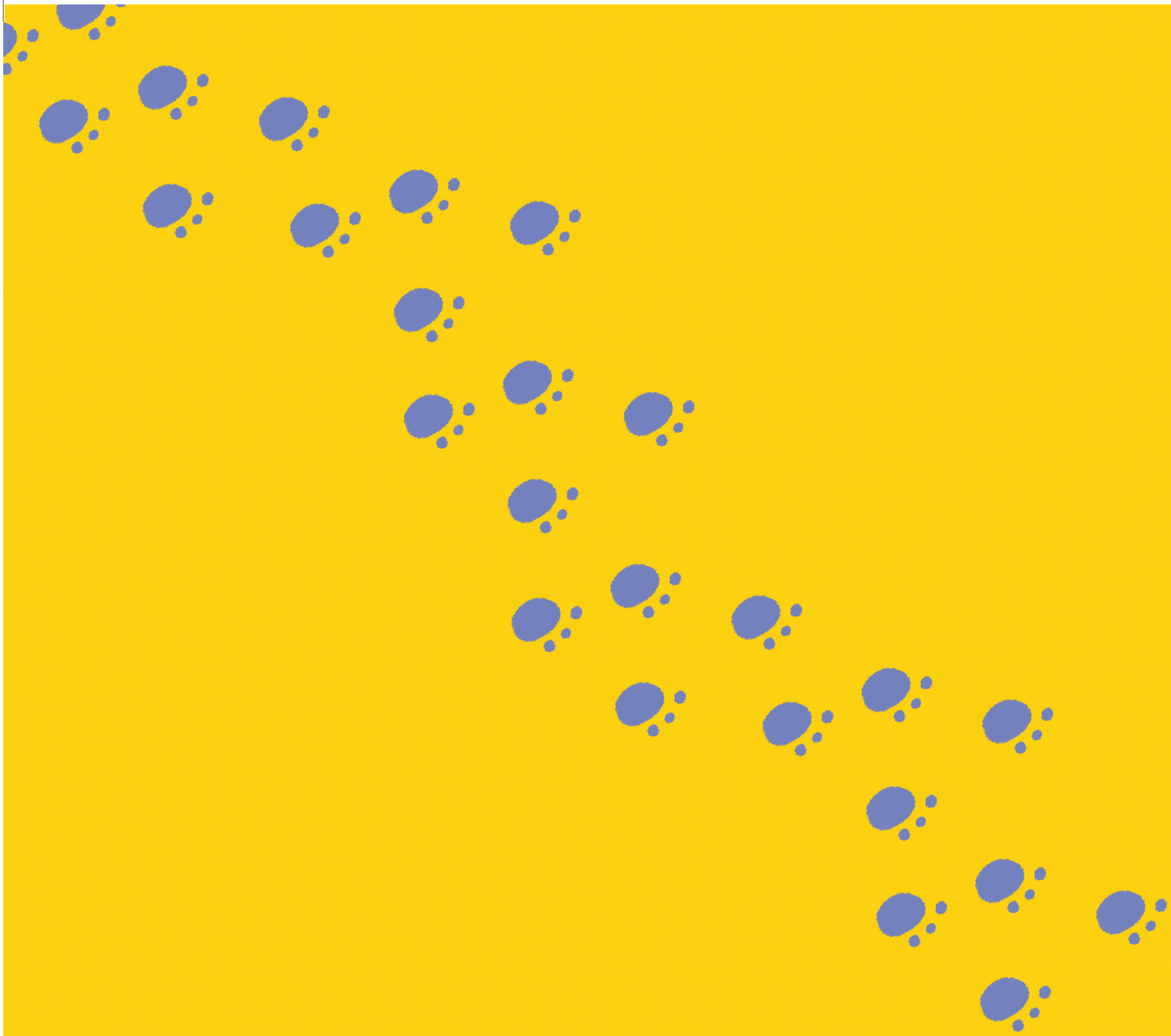

EHC
european haemophilia consortium
Advocating for people with haemophilia and congenital bleeding disorders

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Emma and the PLAYHOUSE

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This book is written for children affected by von Willebrand Disease (VWD) and would like to tell more about it to their immediate family, friends, and teachers at daycare or primary school. It is also aimed at children not living with VWD to help them better understand those living with this disorder, develop compassion, and be supportive of peers.

VWD has many different types and treatments, but not all types have the same characteristics.

For more information about VWD, please refer to the information at the end of this book.

European
von Willebrand Disease
Community

Hi, I'm Emma. I am seven years old and I have von Willebrand Disease. My blood doesn't clot as well as other children's. If I have a wound, my blood cannot properly make a scab on its own. That's why I have to go to the hospital more often.

The doctor sometimes gives me an infusion with a special medicine to help my blood form a scab. Super handy! I find it annoying that I have to go to the hospital more often, but, luckily, I have a very nice doctor.

Do you see the beautiful green house with the red door? That's where I live! I live there with my brother, Kai, my dad, my mum, and my dog, Woof.

Emma and Kai love to play outside all day. As a surprise, Dad built a large playhouse in the garden. Today, Emma and Kai help paint the playhouse in a nice colour.

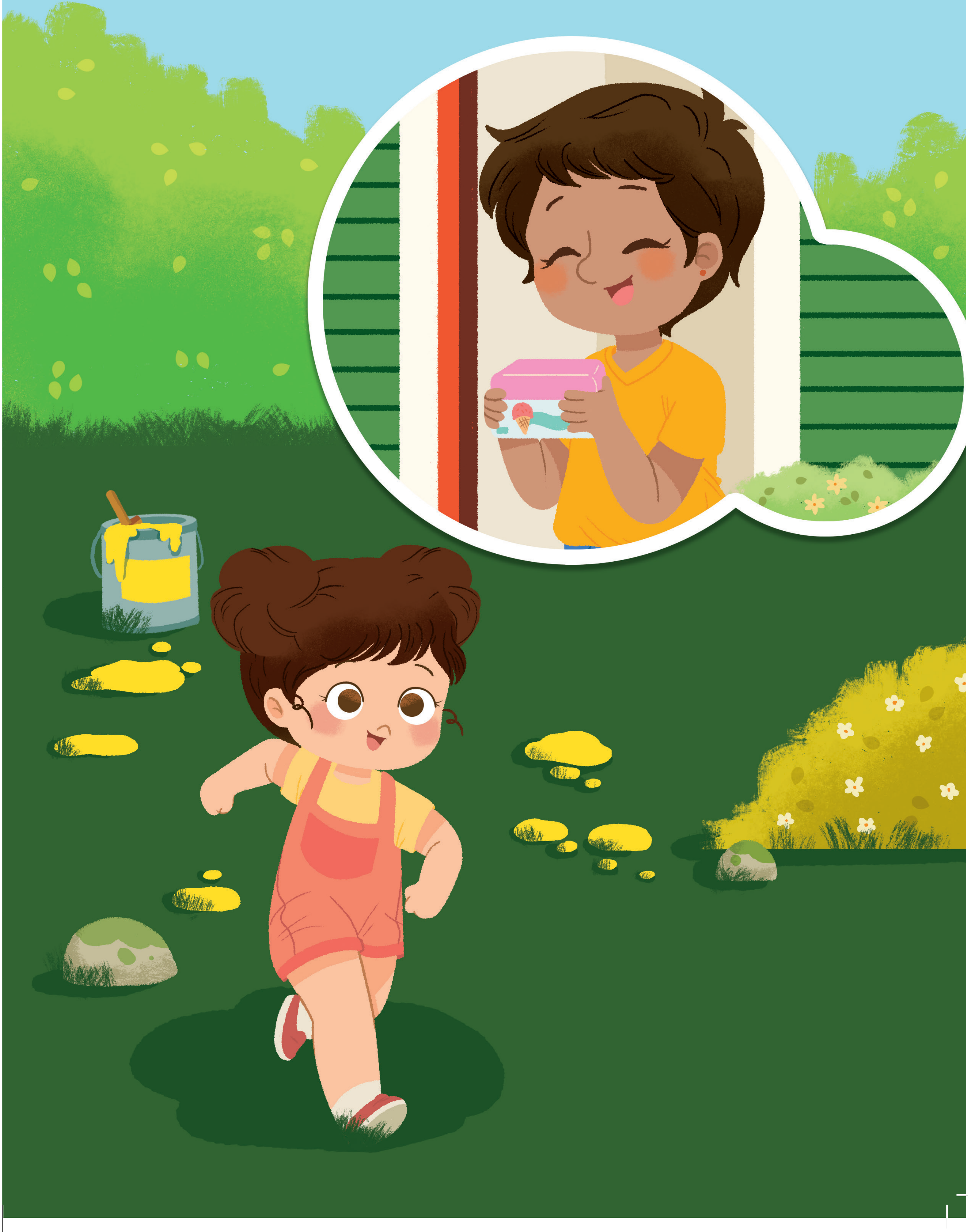
Dad bought a large pot of yellow and purple paint,
and three brushes.

“Are you ready?” Dad calls.
Emma and Kai run to dad and shout loudly “Yesss!!”

Everything is ready in the garden and Woof is lying comfortably. Dad gives Emma and Kai each a brush and opens the jar of yellow paint. Emma dips her brush in the yellow paint and starts painting the playhouse.

Kai is only 5 years old and not that big yet. That's why Dad lets Emma paint upstairs in the playhouse and Kai downstairs. All that painting makes Emma and Kai very warm.

“Time for an ice cream,” Mum calls. Emma jumps up, throws her brush in the bucket, and runs to Mum.



But oh no, the dog, Woof, knocks over a paint bucket while playing next to Kai, and Emma slips on the spilt paint after jumping down the last step of the stairs.

There is blood on her knee and a very large bump on her head.

“Ouch!” Emma cries very loudly. Dad is shocked and runs to Emma. Mum quickly comes with the packaged ice cream and holds it against the big bump on Emma’s head.

"Emma," says Dad, "I'm going to get a plaster for your knee and call the doctor."
Woof gently licks Emma's hand.

Dad calls the doctor in concern and the doctor really wants Emma to come by. Fortunately, the hospital is not very far away.

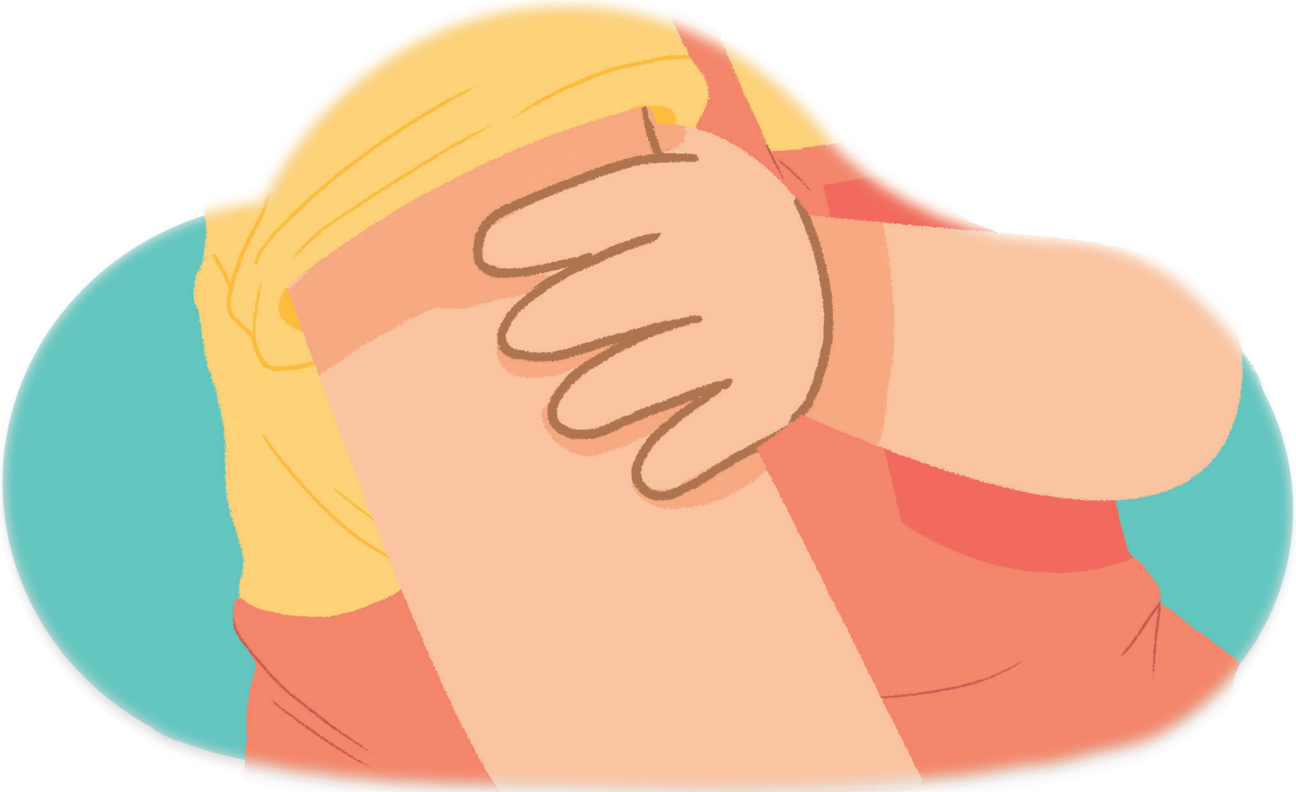
Dad lifts Emma into the car and they all go to the doctor.
Woof stays at home, patiently waiting for them to come back.

"Hello Emma,"
says the doctor.
"Come in quickly."

He looks at the large bump on Emma's head and at her sore knee. Kai looks wide-eyed; he always finds it a little worrying when Emma is at the doctor's.

"Emma," says the doctor. "I'm going to give you an infusion with von Willebrand medicine so that your blood can make a good scab."

Emma knows exactly what to do and she already rolls up her
sleeve. The doctor gets the special medicine
from the refrigerator.



Emma gets a tight, colourful band around her arm and holds her mum's hand. She asks the doctor "Do you want to count to three before you inject?"
The doctor counts to three and pricks Emma in the arm with a tiny needle to give her the special von Willebrand medicine.

Emma only feels a little scratch, and when the doctor is ready,
she can choose a plaster.
Emma chooses a purple plaster with glitter.

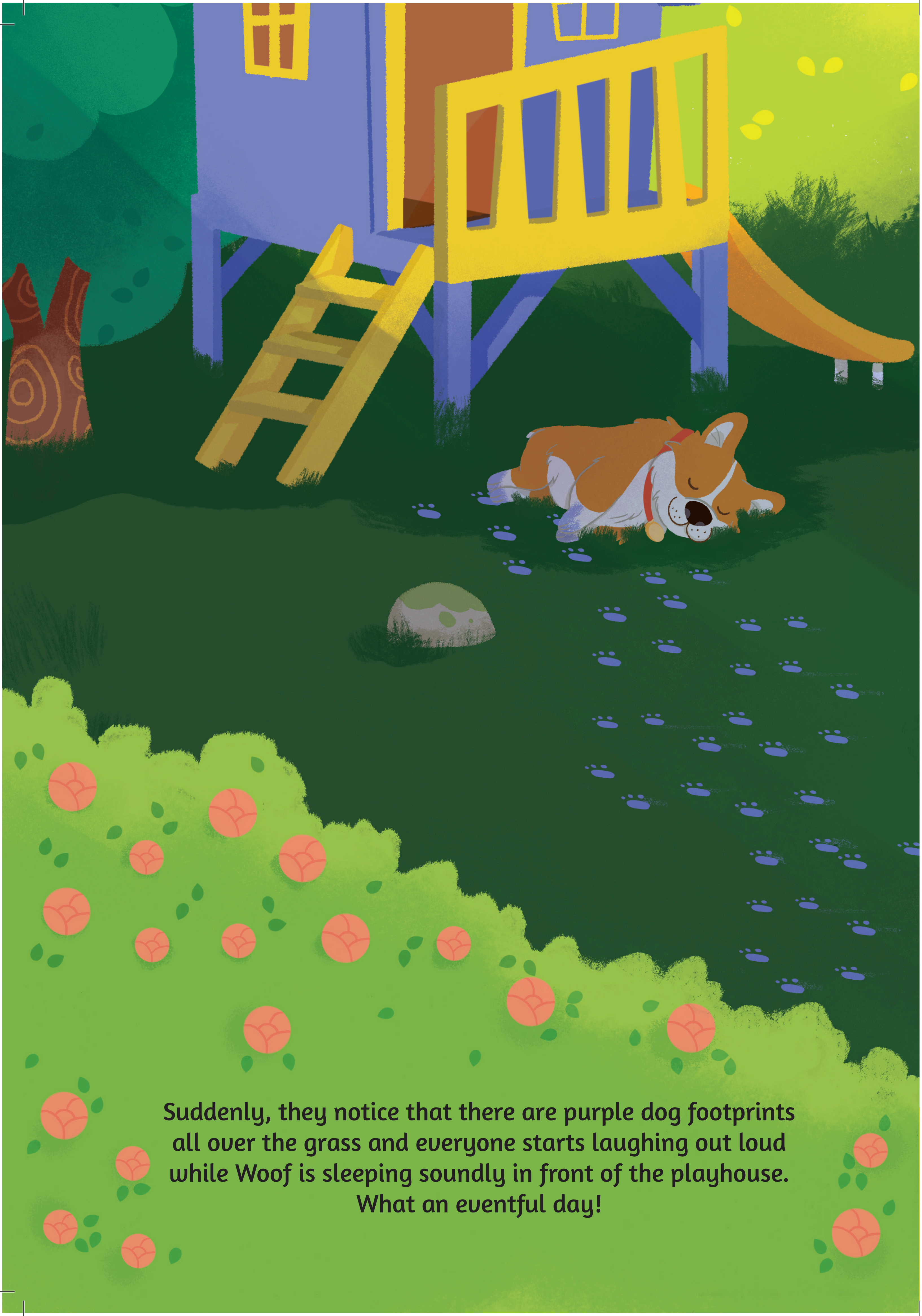
“You did well, Emma,” says the doctor. “You are very brave.”

Kai asks the doctor “Can Emma now scab her blood forever?”

The doctor explains that Emma has too little von Willebrand factor in her blood. Sometimes it’s enough for Emma to form a scab herself, and other times, Emma will need to come back to the hospital to have von Willebrand medication again.

When Emma, Kai, Mum, and Dad get back home, Woof is waiting for them, barking and jumping in circles with joy. Dad and Kai work hard to finish the playhouse.

When their work is done, Mum finally serves the well-earned ice cream and the whole family sits together and marvels at the beautiful playhouse.



Suddenly, they notice that there are purple dog footprints
all over the grass and everyone starts laughing out loud
while Woof is sleeping soundly in front of the playhouse.
What an eventful day!

From the author

After a simple operation, our youngest daughter continued to bleed, requiring multiple operations to stop the bleeding. After extensive research, von Willebrand Disease was diagnosed. Not only our youngest daughter turned out to be affected, but her older sister and we as parents also turned out to have a form of VWD.

A search began... In that search full of questions, the search for recognition and acceptance, we as a family ultimately managed to accept and embrace von Willebrand. For me, as a person, as a mother of two beautiful daughters, I would never have been here without the help, encouragement and recognition I received from a very special person involved in the Dutch patient organisation.

I once wrote a small compact book for my daughters in which I explained in simple words what von Willebrand meant to them. I gave this booklet to close family and friends, the teachers at the daycare center, to the teachers at the primary school, and to the parents of friends. Thanks to that small, simple book, we did not have to explain again and again what von Willebrand meant to them, what had to be paid attention to or how to act. This booklet was the inspiration for writing this book.

I hope that this book, despite the many differences in the clinical picture that von Willebrand knows, can contribute to the first steps at daycare, primary school, playing with friends or explaining it to close family and friends.

For more information about von Willebrand Disease, I would like to refer you to the EHC VWD Committee website at https://community.ehc.eu/focus-area/von-willebrand-disease-vwd/ or scan the QR code below to visit the site.

Cathy Verbraeken

Acknowledgement: This book was developed with the support of the EHC VWD Committee.