

CHILDREN OF GENETICS

Sonia Goerger and Élodie Garcia

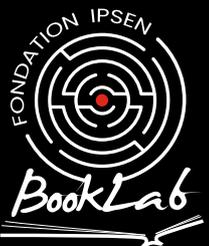


The Super Family of Birgit, the Rabbit



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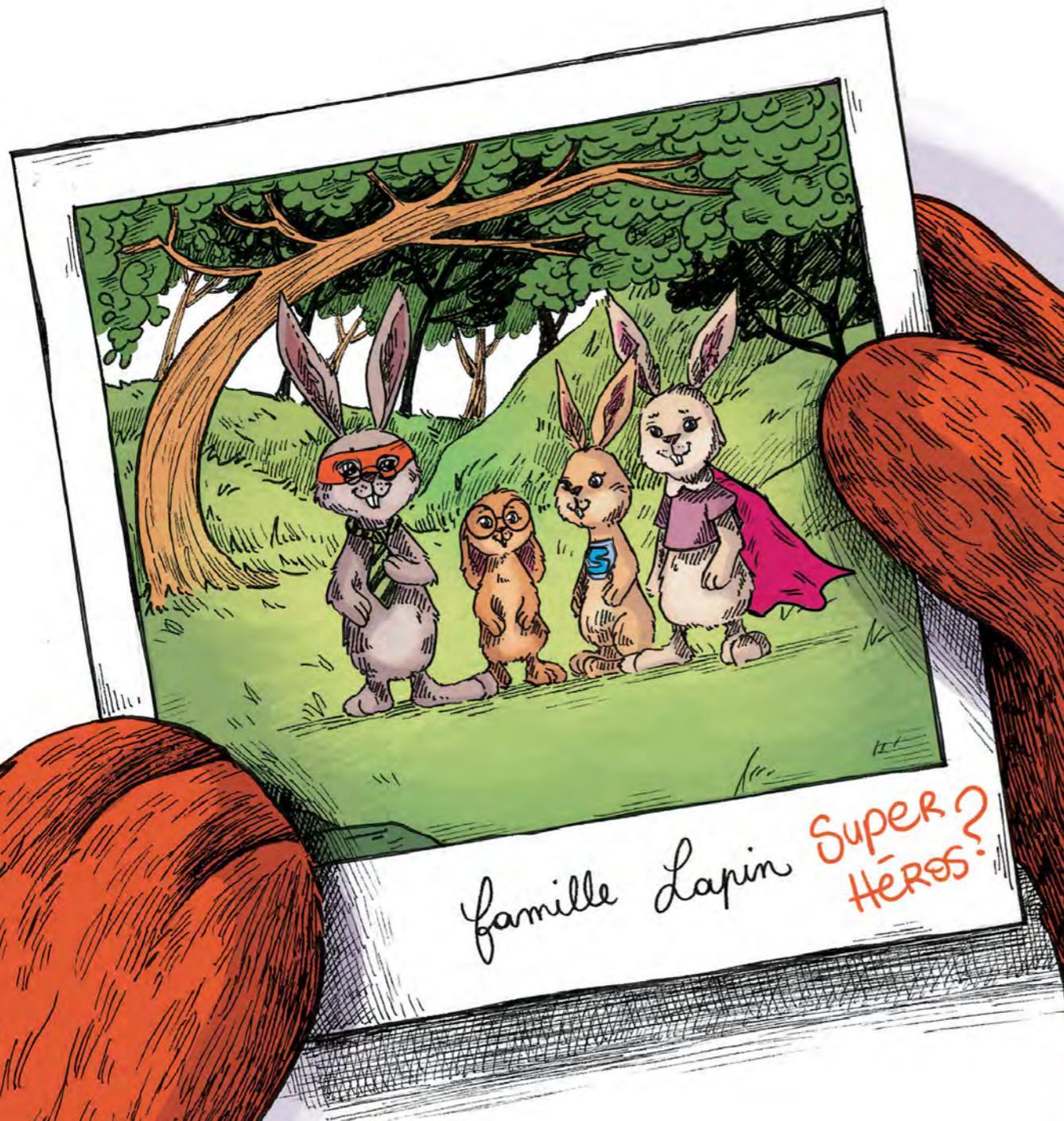


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The Super Family of Birgit, the Rabbit

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Birgit, the little rabbit, lives with her parents and her big sister, Capucine. Birgit has had a disease since birth. Because of this disease, at the age of seven, she cannot walk or talk or see very well. But it is not for this reason that the Rabbit family is known throughout the forest...

It is said that the Rabbit family is a family of superheroes!

Real superheroes, with real superpowers!

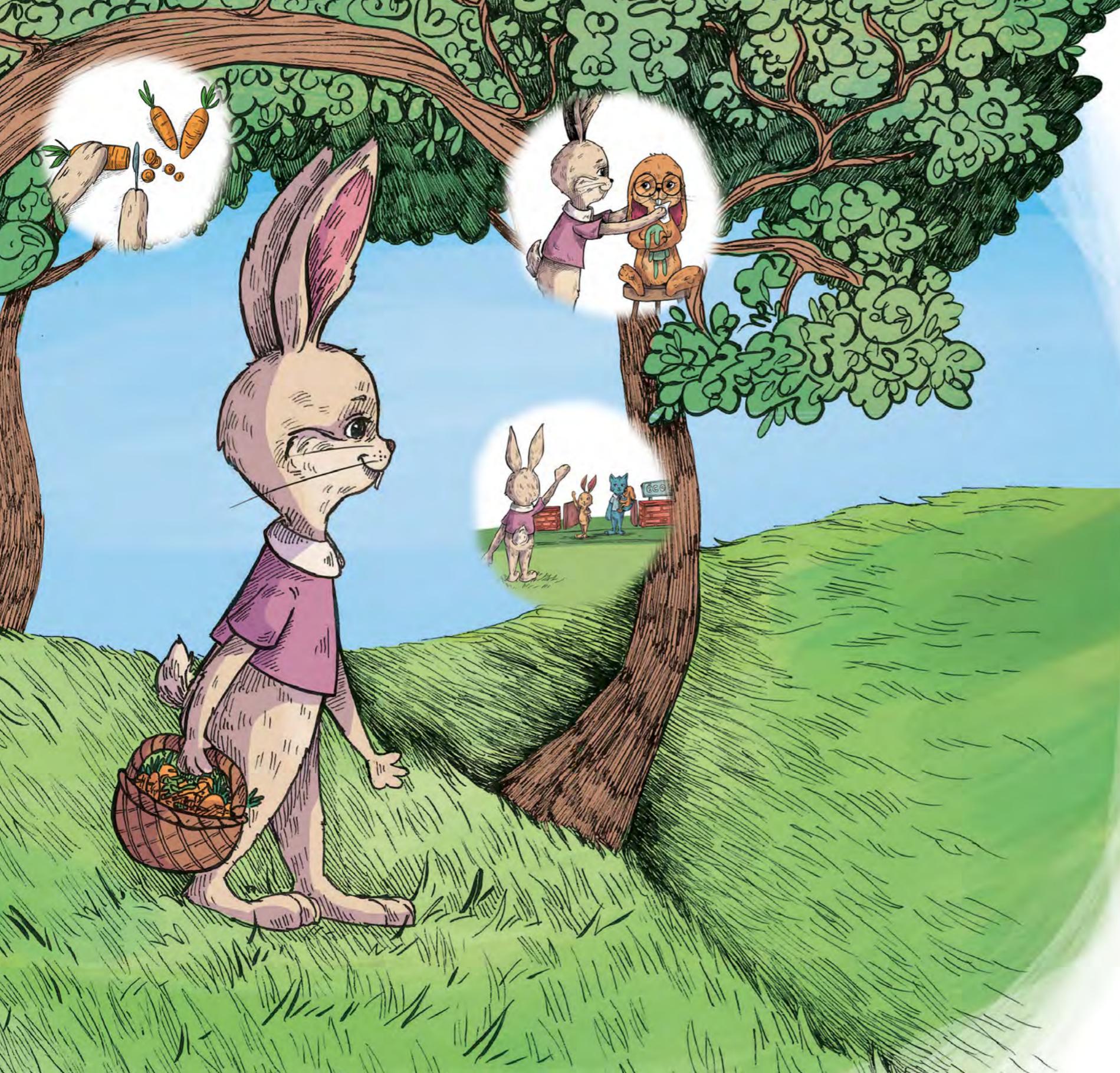
"An extraordinary child calls for extraordinary parents," the animals of the forest like to say.

When a mischievous and very curious little squirrel named Mayeul hears about this legend, he can think of only one thing: discovering the secret of the Rabbit family.

To successfully carry out his mission, the little squirrel decides to discretely observe the Rabbit family.

The first day, he follows Mama Rabbit during her very busy day.

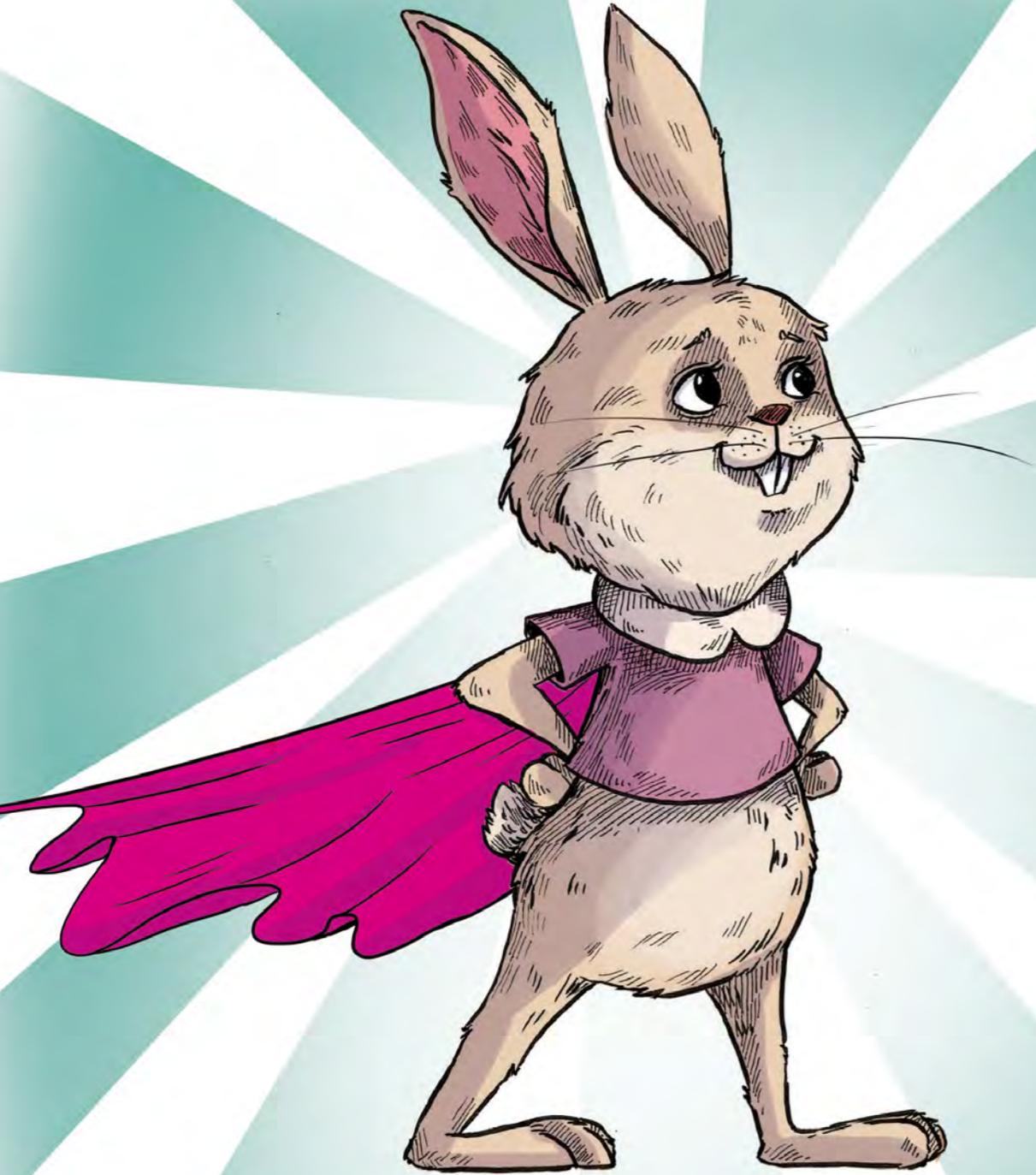




Mama Rabbit gets up really early and starts her day by preparing breakfast for the whole family. Next, she gives Birgit her medical care and then helps her to wash and dress. Once her two girls are dropped off at school, she rushes off to go grocery shopping before heading to work.

Later that day, she returns to pick up Birgit and Capucine, makes several phone calls to book medical appointments for Birgit, helps her take her bath, prepares dinner, helps Capucine with her homework, and still finds time at the end of the day to do a puzzle with Birgit before bedtime.





Dizzy and exhausted from this intense pace, Mayeul asks himself how Mama Rabbit is able to do so many things in a single day.

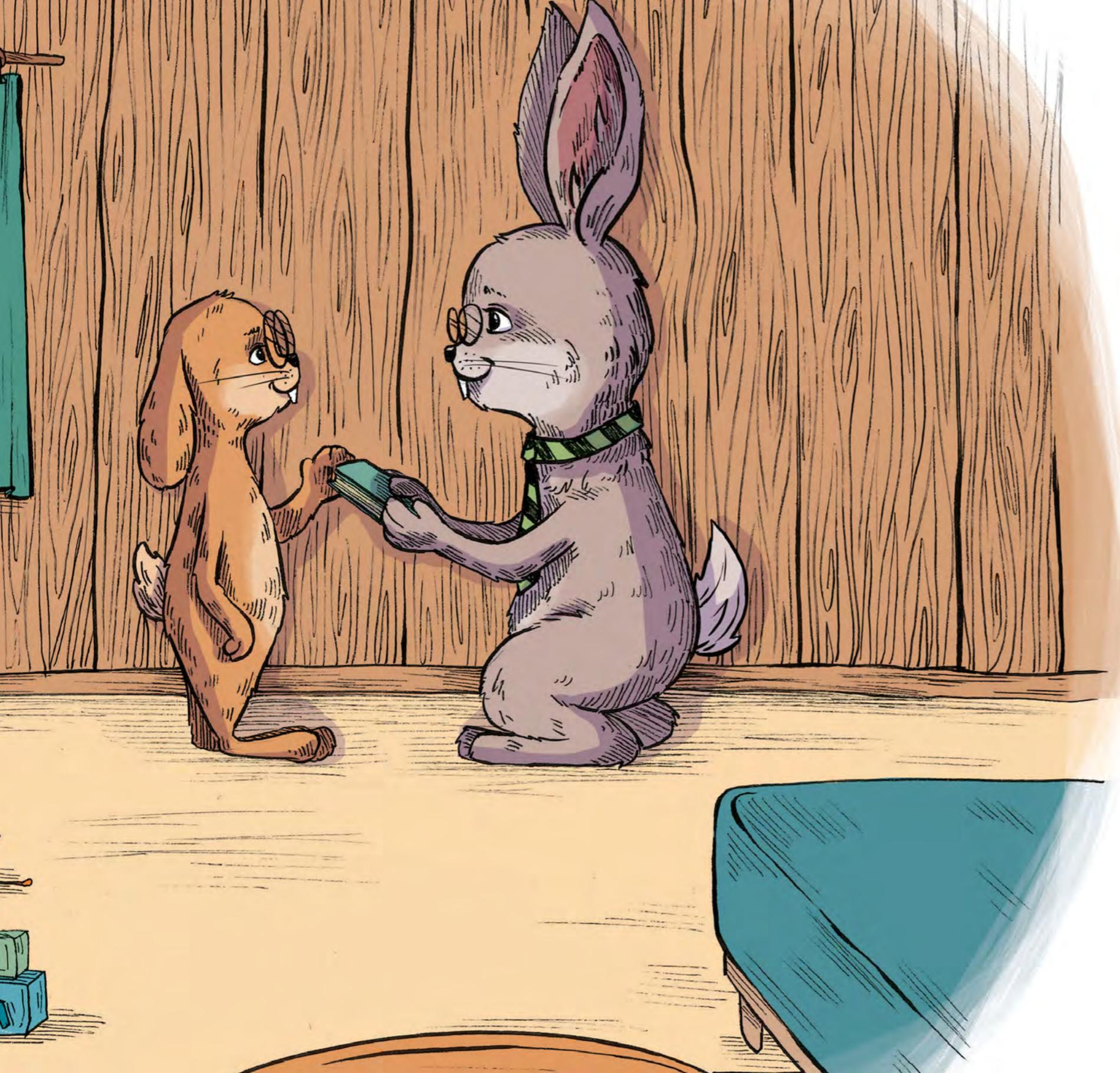
Then suddenly it hits him.

“But of course! Mama Rabbit’s superpower is super speed! She is faster than light!” Mayeul exclaims, delighted.

On the second day, Mayeul decides to spy on Papa Rabbit. Today, Papa Rabbit stays home to take care of Birgit. Like every Tuesday, Birgit's physiotherapist arrives for a rehabilitation session. But Birgit does not feel like doing it today.

She screams, stomps her feet and gets upset. As she cannot speak, it is difficult to understand what she needs.





Papa Rabbit crouches down to her level and speaks to her calmly:

“Birgit, my darling, what’s wrong?”

Birgit watches her father closely, makes some big gestures and lets out some little grunts. With that, her father understands.

“The book we didn’t finish reading last night?! You want to know how the story ends, is that it?” asks Papa Rabbit.

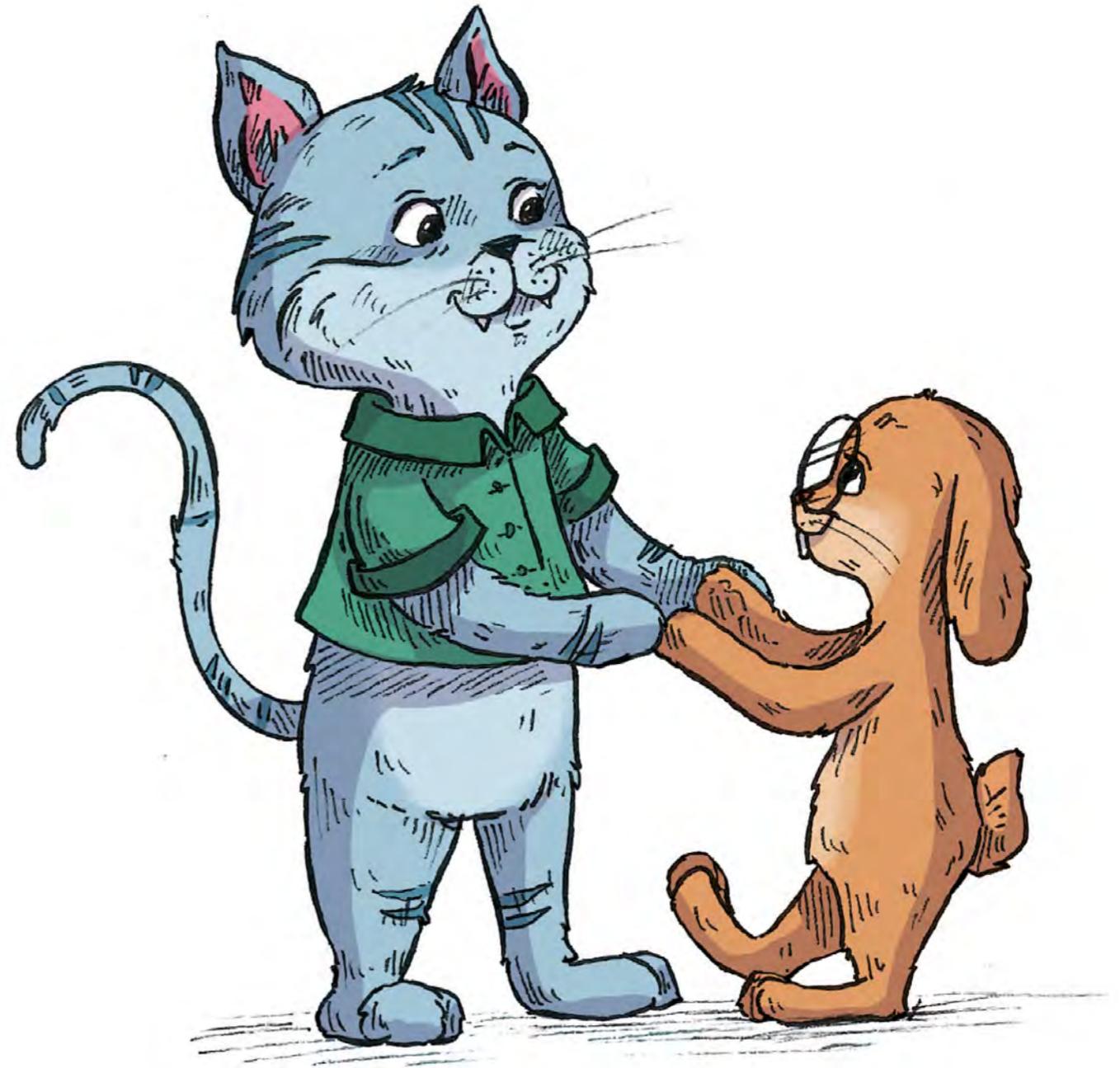
Birgit nods her head, with a big smile.

Papa Rabbit then replies:

“Okay, Birgit, I will read you the end of the story, but after that, you must do your physiotherapy session. And I want you to give it your all!”

Birgit and Papa Rabbit seal the deal with a handshake.

And the rest of the physiotherapy session continues, with everyone in good spirits.





Mayeul is both stunned and impressed. How was Papa Rabbit able to understand Birgit when she did not speak a single word?

“Oh, I know!” exclaims Mayeul.

“Papa Rabbit can read minds!

Telepathy is his superpower!”

Pleased with his new discovery, Mayeul heads home, determined to return the next day for a final day of observation.

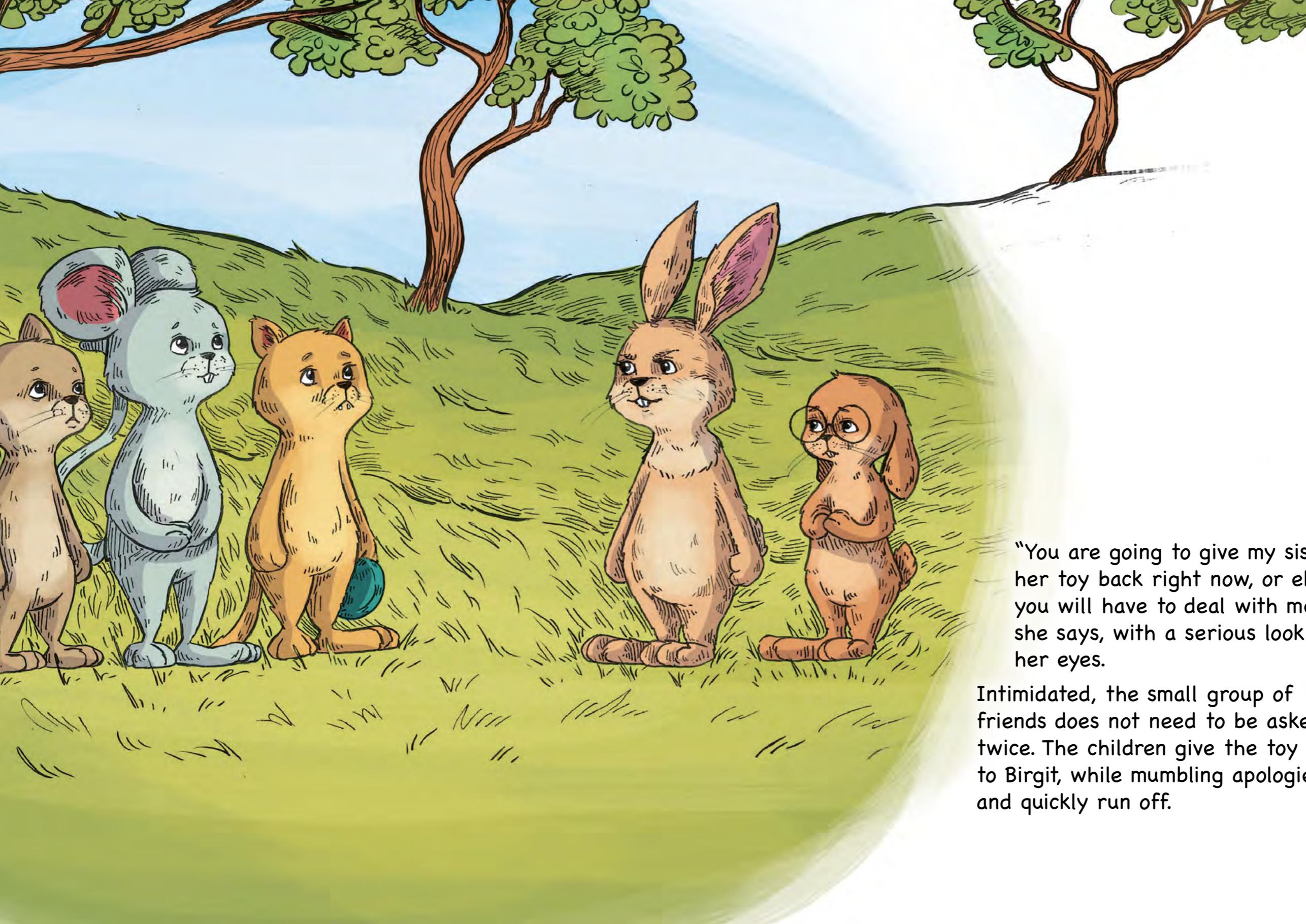


After Mama and Papa Rabbit, the next one to be spied on is Capucine, Birgit's big sister.

The weather is beautiful today. The Rabbit family decides to have a picnic in the park. Perched in a tree, Mayeul has a perfect view of the playground where Capucine and Birgit are playing together.

At the age of ten, Capucine is very caring towards her sister.

A small group of children approach Birgit and start bothering her.



"You are going to give my sister her toy back right now, or else you will have to deal with me!" she says, with a serious look in her eyes.

Intimidated, the small group of friends does not need to be asked twice. The children give the toy back to Birgit, while mumbling apologies, and quickly run off.



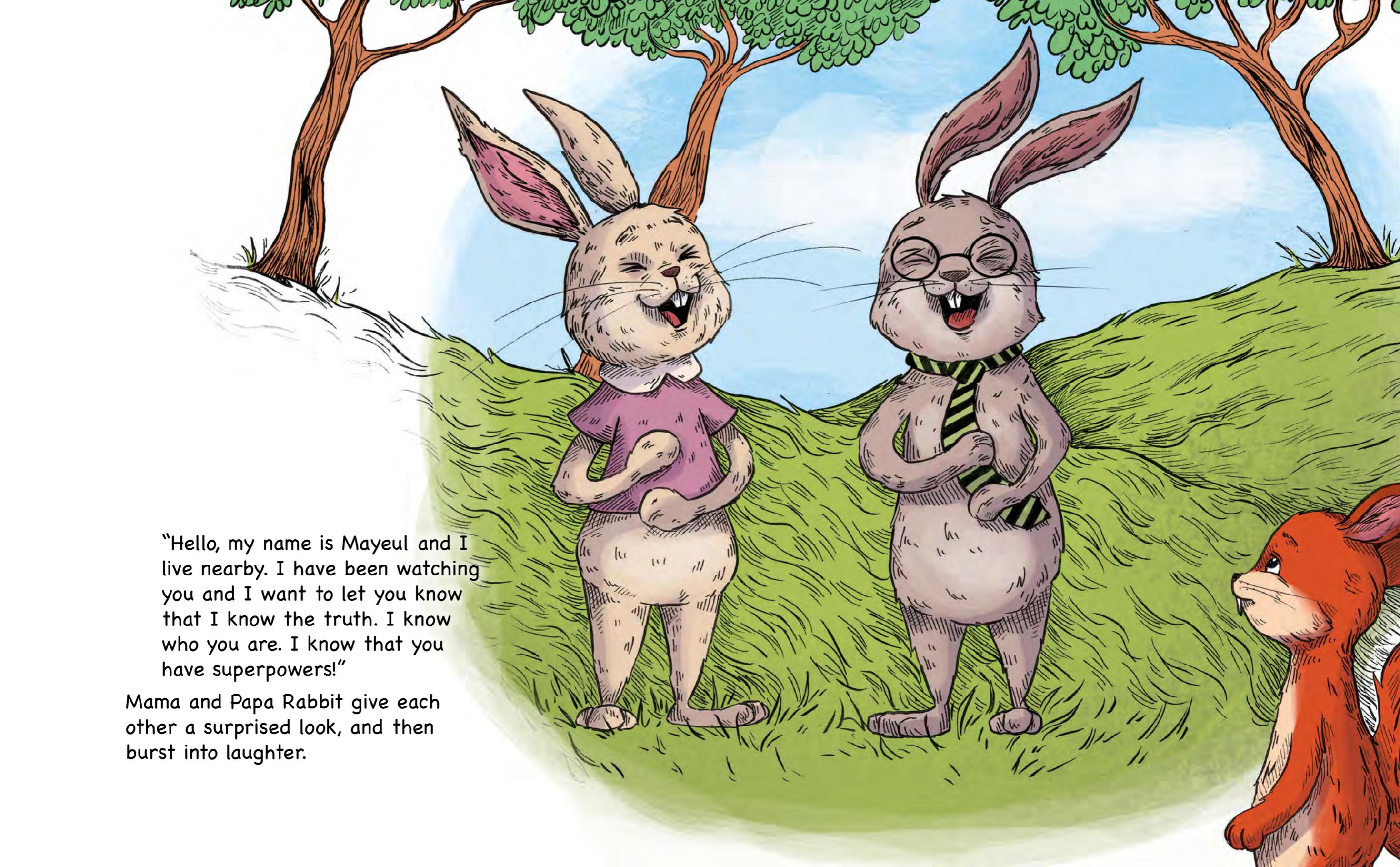
Mayeul, who had not missed a second of the spectacle, smiles.

"What strength and what courage!" he thinks, admiring Capucine.
"Defending the weak, now that is what I call the attitude of a superhero!" he concludes with pride.

Mayeul now has all the proof that he needs! His investigation has come to an end. Tomorrow, he will talk to the Rabbit family and tell them that he has discovered their secret...



The next day, upon arriving at the Rabbit family's house, the little squirrel is about to ring the doorbell when he hears laughter coming from the garden. He walks that way and finds the Rabbit family all together. Taking a deep breath, he calls out to them.



“Hello, my name is Mayeul and I live nearby. I have been watching you and I want to let you know that I know the truth. I know who you are. I know that you have superpowers!”

Mama and Papa Rabbit give each other a surprised look, and then burst into laughter.



“We are not superheroes! We are just like any other parents,” declares Mama Rabbit.

– “And we also have our limitations and weaknesses, you know,” adds Papa Rabbit. “We do our best. But sometimes, it is hard. There are ups and downs.”

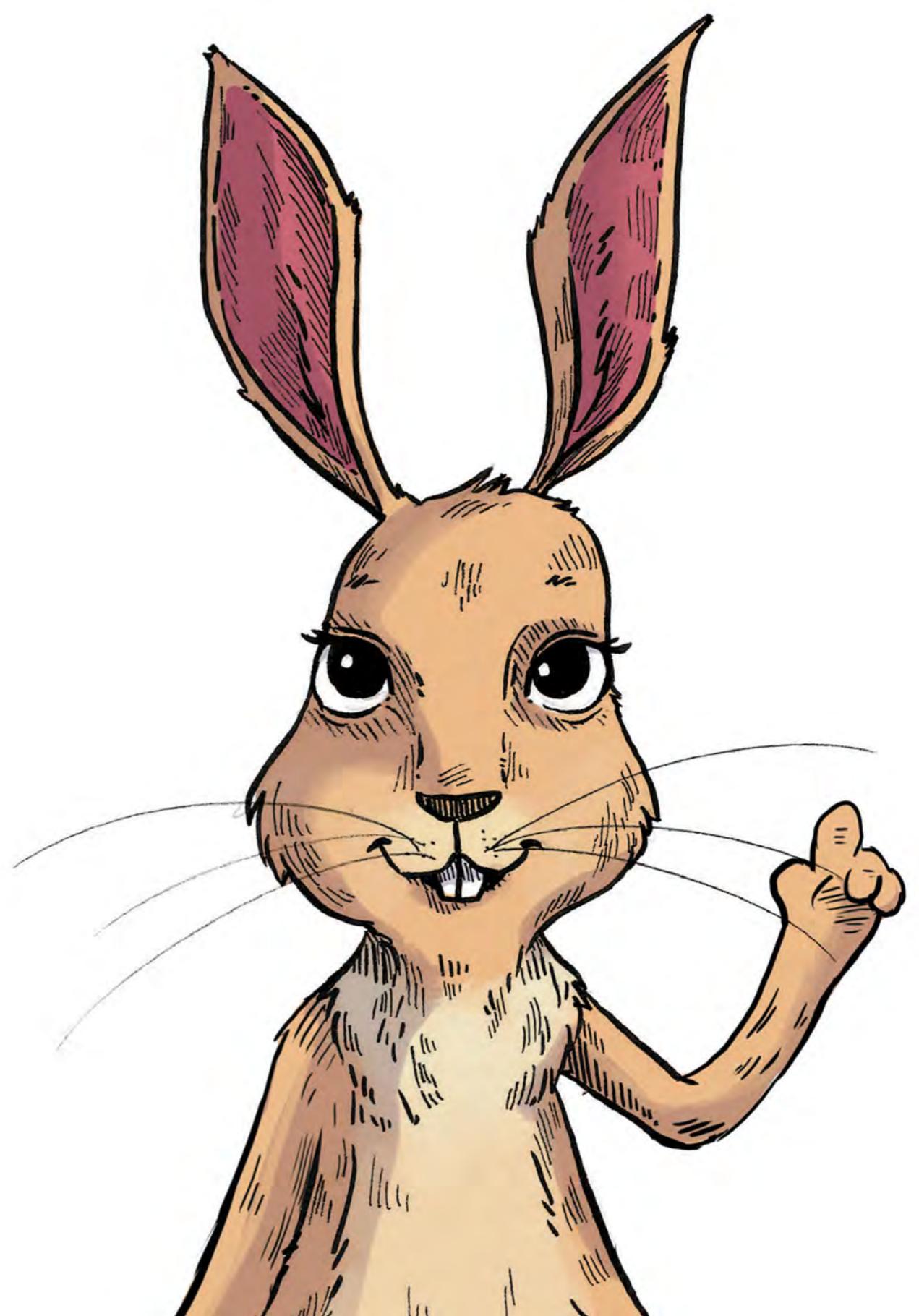
– “Luckily, we are very well supported! Birgit and Capucine’s grandmother helps us a lot and takes over when we need it,” explains Mama Rabbit.

Mayeul frowns and looks at them skeptically. He knows what he saw. They are denying it to keep their secret. It makes perfect sense!

Capucine then has an idea:

“Spend the day with us! And without hiding this time! We will talk again tonight!” she proposes with enthusiasm.

Mayeul happily accepts.



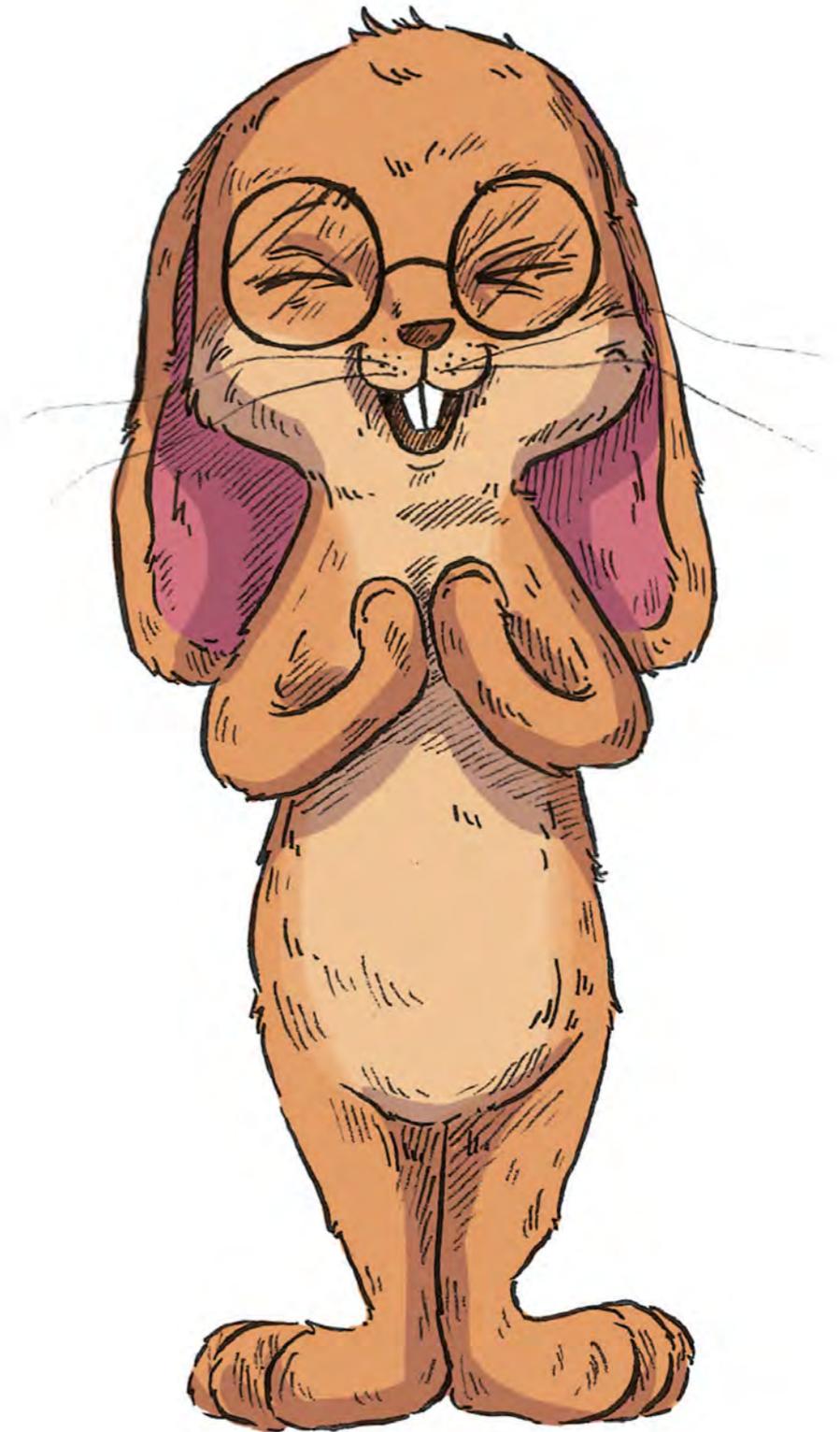


Mayeul spends a lovely day with the Rabbit family. They do lots of activities and play games together. He gets to know Capucine and Birgit, who he now considers to be his friends. The day is also interrupted by Birgit crying whenever she feels pain. These moments are not easy, but Mama and Papa Rabbit are always by her side to calm her down and make her smile again.

At the end of the day, Mayeul is happy. Before he leaves the Rabbit family, he tells them:

“You may not be superheroes, but you are super parents and a super big sister!”

Birgit claps her hands and lets out little squeals of joy, as if to agree with what was said by her new squirrel friend.





Mayeul continues:

“And you know what? You have a superpower! It is even the strongest of them all!”

– “Which one?” Mama Rabbit manages to ask, already very moved.

– “The love that you have for each other!” exclaims Mayeul, before turning away to leave.

Mama and Papa Rabbit take each other's hand. With tears of joy and stars in their eyes, they join their adorable daughters. Our four heroes then share a super hug...

Because, together, they are quite simply invincible.

Start the discussion!

Continue exploring this story with the children. The questions on the next page will help guide your thoughts.





What do you think about the Rabbit family?

Why do you think that Mayeul, the little squirrel, finds the Rabbit family so extraordinary?

What do you think about their superpowers?

Do you think that all parents can have superpowers?

Would you also like to have one or more superpowers so that you can help others? Which ones?

Do you think that it might be difficult to care for a child like Birgit, who has had a disease since birth?

How do you think this family's daily life might be different from that of other families?

About the situation of caregivers

When you are the parent of a child with a disease or disability, you inevitably become a parent caregiver. In France it is estimated that 1 in 5 people is an informal caregiver, which represents 9.5 million caregivers.

Between medical care, administrative tasks, and the challenges of daily life, being an informal caregiver is far from easy. It requires an enormous amount of time and dedication, and has an impact on the health and the professional and personal lives of those concerned.

In 2021, the multidisciplinary and participatory CASEPRA project (led by the Economic Laboratory of Dijon (LEDi) at the University of Burgundy) aimed to shine light on the role of parent caregivers for children with or suspected of having a rare disease and/or rare disability, by seeking to characterize the nature, diversity, and intensity of the help provided by parents, as well as the impact on their professional lives.

To learn more about the project:



This project has been awarded two grants: CASEPRA-Pil has been supported by the French Foundation for Rare Diseases (Call for Projects on «Human and Social Sciences and Rare Diseases» 2020). CASEPRA has been funded by the French National Solidarity Fund for Autonomy (CNSA in French) under the research program «Autonomy for the Elderly and People with Disabilities» led by the French Institute for Public Health Research (IReSP in French; BLC20_218793).

About the author

Sonia Goerger is a medical secretary who has been welcoming and meeting patients with genetic conditions for many years. This inspired her to create the “Children of Genetics” book series for children.

The books of this collection address the challenges that patients may experience on a daily basis, using simple terms and endearing characters. To bring them to life, Sonia Goerger collaborated with Christine Juif, a clinical psychologist, who supports patients with genetic diseases and their families throughout the diagnostic process.

About the illustrator

After being a graphic designer for several years, Élodie Garcia transitioned to a career as an author and illustrator of children's books and comics. With her delicate and refined drawing style, she is able to gently approach sometimes difficult topics. By illustrating the « Children of Genetics » book collection, Élodie Garcia hopes to help families affected by rare diseases.

About the ARGAD Association

The Association for Research in Genetics and Support for Families and Professionals of Dijon-Burgundy (ARGAD in French) is a non-profit organization under the French 1901 law status, created in September 2010.

This association supports the development of the FHU-TRANSLAD through a number of actions:

- Improving the conditions of reception and care for patients with rare diseases in Burgundy, France,
- Disseminating information on rare diseases by organizing dedicated meetings,
- Assisting doctors and healthcare professionals involved in the care of rare genetic disease patients with furthering their training and increasing their knowledge in this field
- Supporting clinical and biological research activities focused on the genetics of developmental anomalies in Burgundy, France.

To support the ARGAD association and its mission, visit:

<http://www.translad.org/>



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Birgit, a little rabbit with a rare disease, lives with her big sister, Capucine, and her parents. In the forest, legend has it that they are real superheroes. Mayeul, the curious little squirrel, leads an investigation to uncover their secret. Is it superpowers or simply the magic of everyday life?



“Children face many challenges in their lives. Disease is hard to discuss. These books explain that every child is powerful and that their spirit is greater than any disease.”

– James A. Levine

MD, PhD, Professor, Fondation Ipsen, President
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