

CHILDREN OF GENETICS

Sonia Goerger and Élodie Garcia

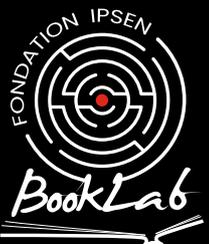


# Hugo and Eleanor, the Elder Boars



European  
Reference  
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for rare or low prevalence  
complex diseases

Network  
Intellectual Disability  
and Congenital  
Malformations (ERN ITHACA)



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# Hugo and Eleanor, the Elder Boars

CHILDREN OF GENETICS





Once upon a time, in the forest, by a small clearing, lived a family of boars. Mummy Sow and Daddy Boar had four children: two young teenage boars called Eleanor and Hugo, and two little boarlets, Olivia and Leo.

A seemingly ordinary boar family, except that the two boarlets had a disease that prevented them from seeing properly and having a good sense of smell. They also had difficulty walking and they could be very irritable, which sometimes made them completely out of control.

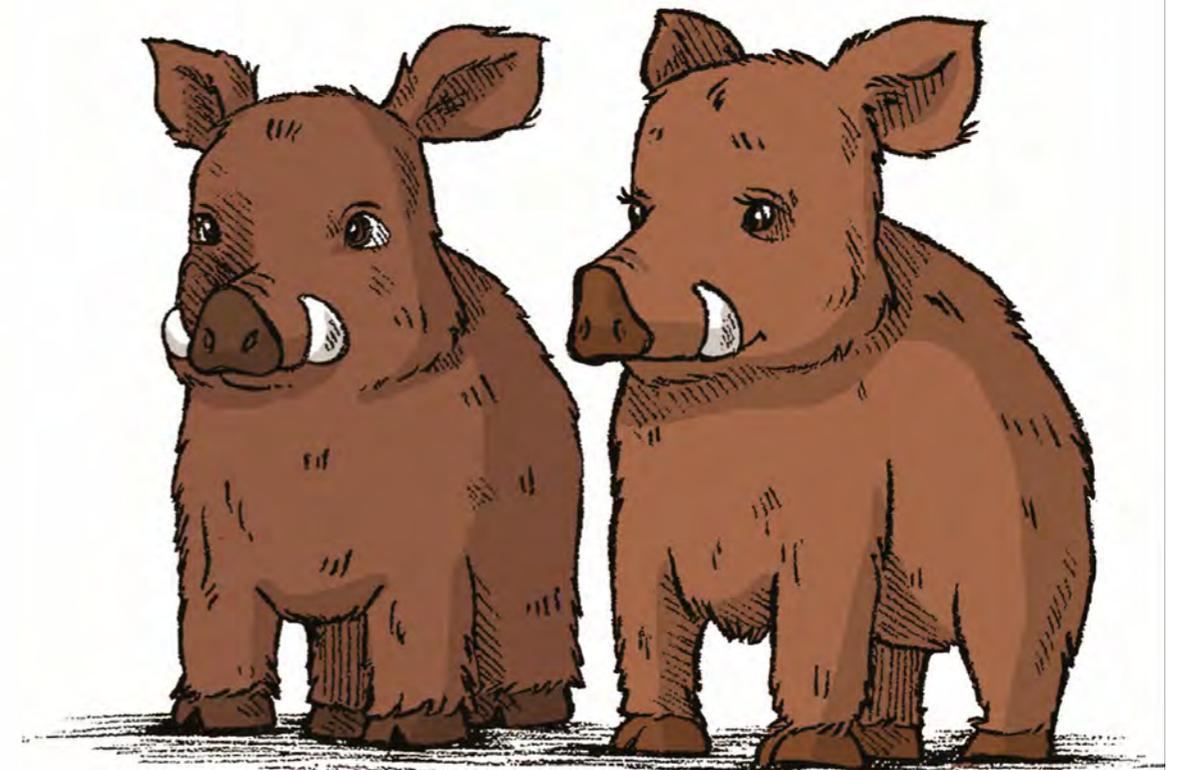




That morning, Mummy and Daddy Boar were about to go to the woods to look for food. Before leaving, they once again gave their advice to the two elders:

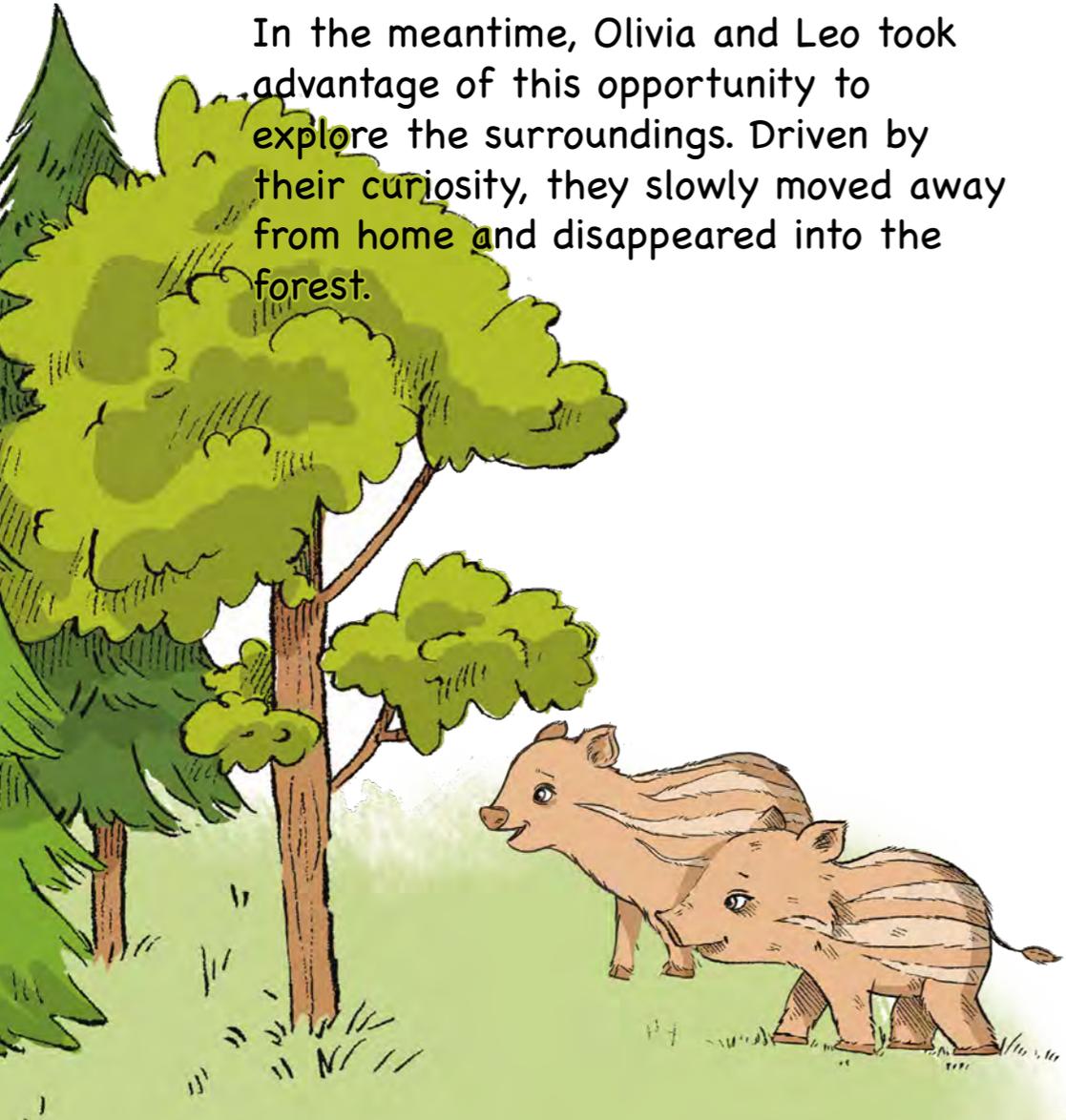
"While we are away, we entrust you with the care of your little brother and sister. Take good care of them and don't let them out of your sight."

"Yes, yes..." Eleanor and Hugo answered with a sigh, half listening.



Once their parents had left, the young boars went about their business, leaving the little boarlets unattended. Hugo comfortably settled down in front of the TV, while Eleanor sat in a corner to eat acorns.

In the meantime, Olivia and Leo took advantage of this opportunity to explore the surroundings. Driven by their curiosity, they slowly moved away from home and disappeared into the forest.





Surprised by the silence in the house, Eleanor left her acorns behind and went to see what her little brother and sister were doing. She then realised they had left, and she ran to Hugo.

“Olivia and Leo have disappeared! We have to look for them!”, Eleanor yelled completely panicked.

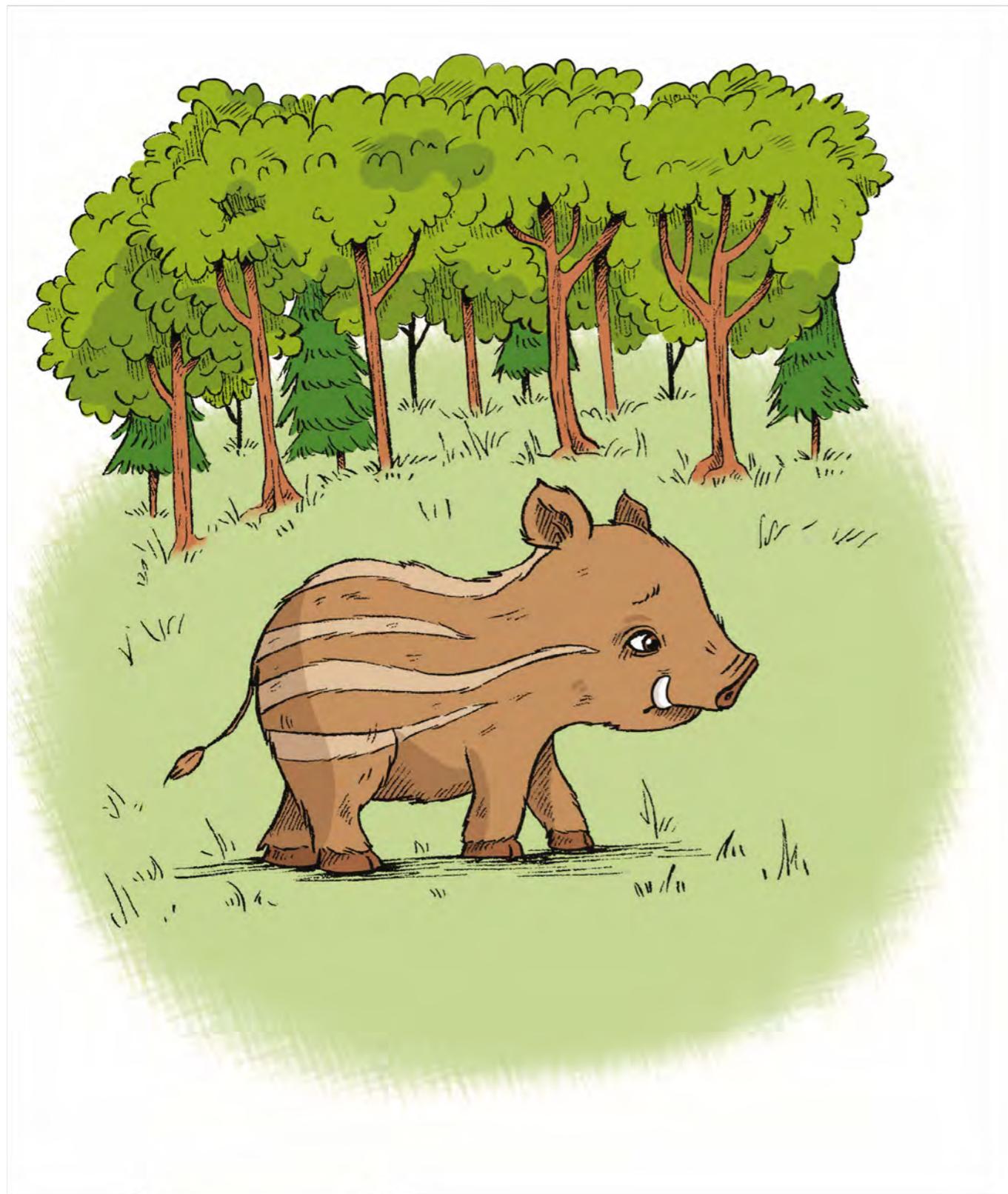
“Calm down! They must be somewhere in the house doing something stupid as usual! Go and look for them yourself”, Hugo replied, totally indifferent.

Upset and frightened, Eleanor went into the woods alone to look for the two intrepid boarlets.

In the meantime, the two little ones got completely lost. Seeing almost nothing, they wandered awkwardly through the forest and kept bumping into trees. Their lack of sense of smell prevented them from finding their way back...

Leo fell into a trap set on the ground and found himself immobilised, his hoof was stuck. And Olivia was so exhausted that she ended up collapsing at the foot of a tree.





On the path, Eleanor could not help but imagine the worst.

“If anything happens to them, Mum and Dad will never forgive me! And neither will I,” she thought.

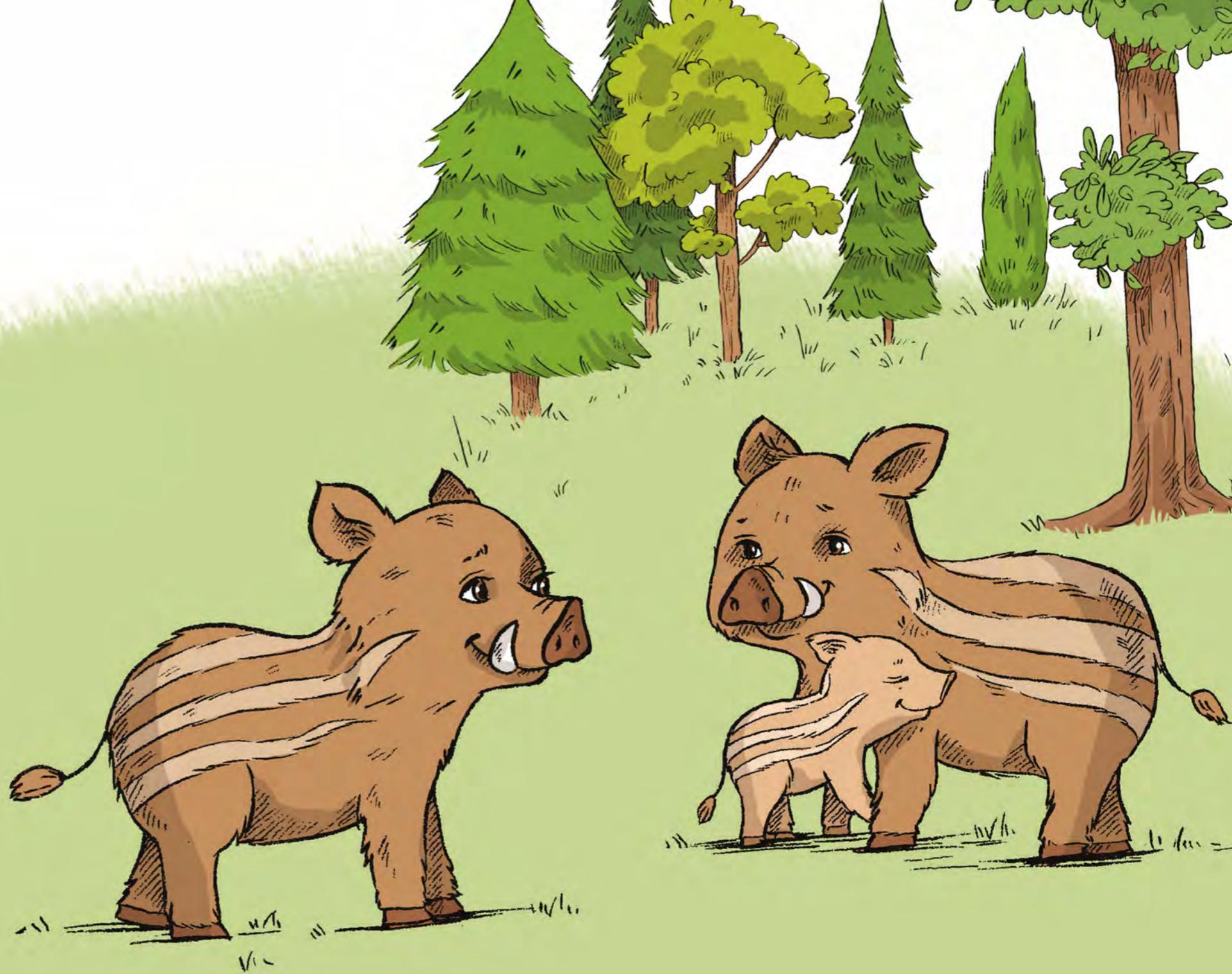
“Why didn’t I listen to them? Don’t let them out of your sight, they said...” the young teenager kept thinking of her parents’ words, and now she could not stop her tears from running.

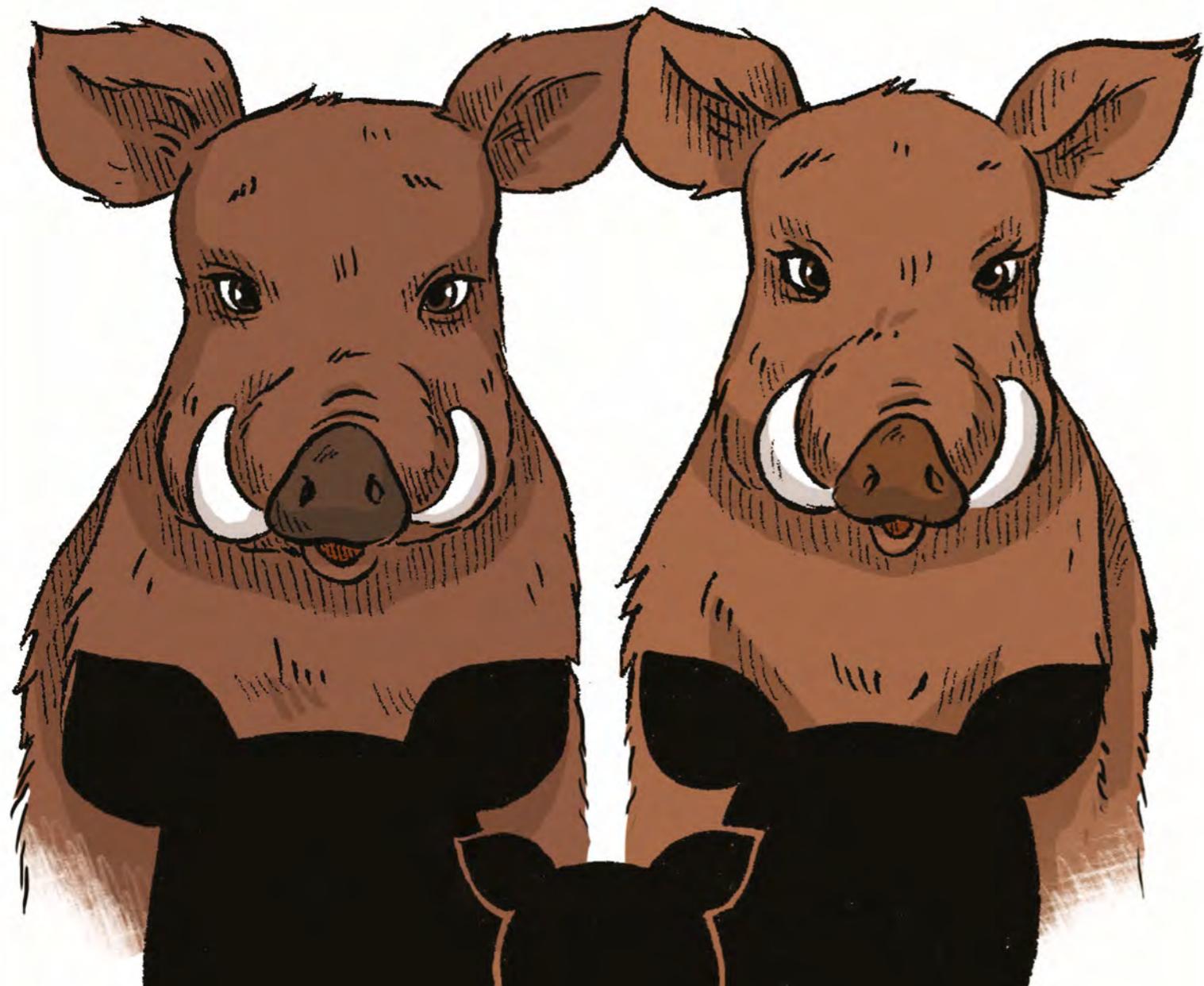
Suddenly, Eleanor saw a motionless figure in the distance. It was Leo! What a relief ! She ran to him and tried to free him from his trap, in vain.

That was when she heard behind her:

“Need help?”

Eleanor turned around and, thrilled, saw Hugo. Too proud to admit it, the young boar was also very worried about his brother and sister. With the help of their tusks, the two teenagers managed to free Leo from his trap.





After several hours of searching, and unfortunately not being able to find Olivia, the children decided to return home and wondered how to tell their parents the bad news. Their parents had just got home and had been waiting for the children on the doorstep.

“Ah, finally! Where have you been? We were worried!” Mummy Sow exclaimed.

“Why does Leo have a bloody hoof? And where is Olivia?” Daddy Boar asked worryingly.

As the two young boars were plucking up the courage to tell what had happened, a boarlet wearing glasses appeared.

Mummy Boar was surprised. She lifted the glasses off the boarlet's nose and confirmed that it was Olivia.

"When I woke up, I found some glasses hidden under the leaves. Thanks to them, I was able to see better, and I managed to find my way back," Olivia explains, proud of having managed to find her way back on her own for once.

Each child then told what they had experienced to their parents, whose faces distorted as they were told the details of their children's crazy adventure.



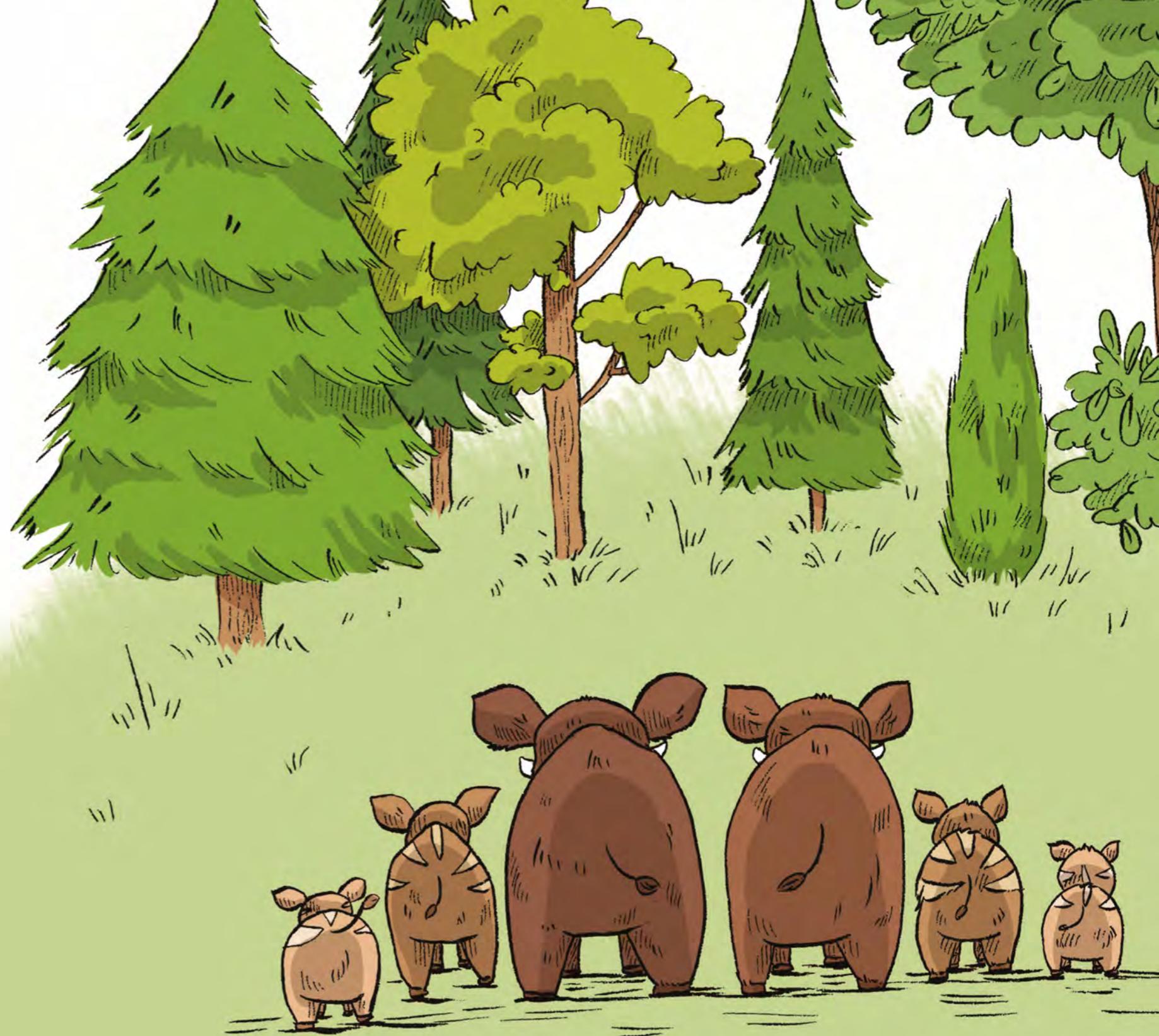


The whole Boar family breathed a sigh of relief, happy and reassured that the story had a happy ending.

"At least, this has taught us one lesson...", Daddy Boar said to his two elder children.

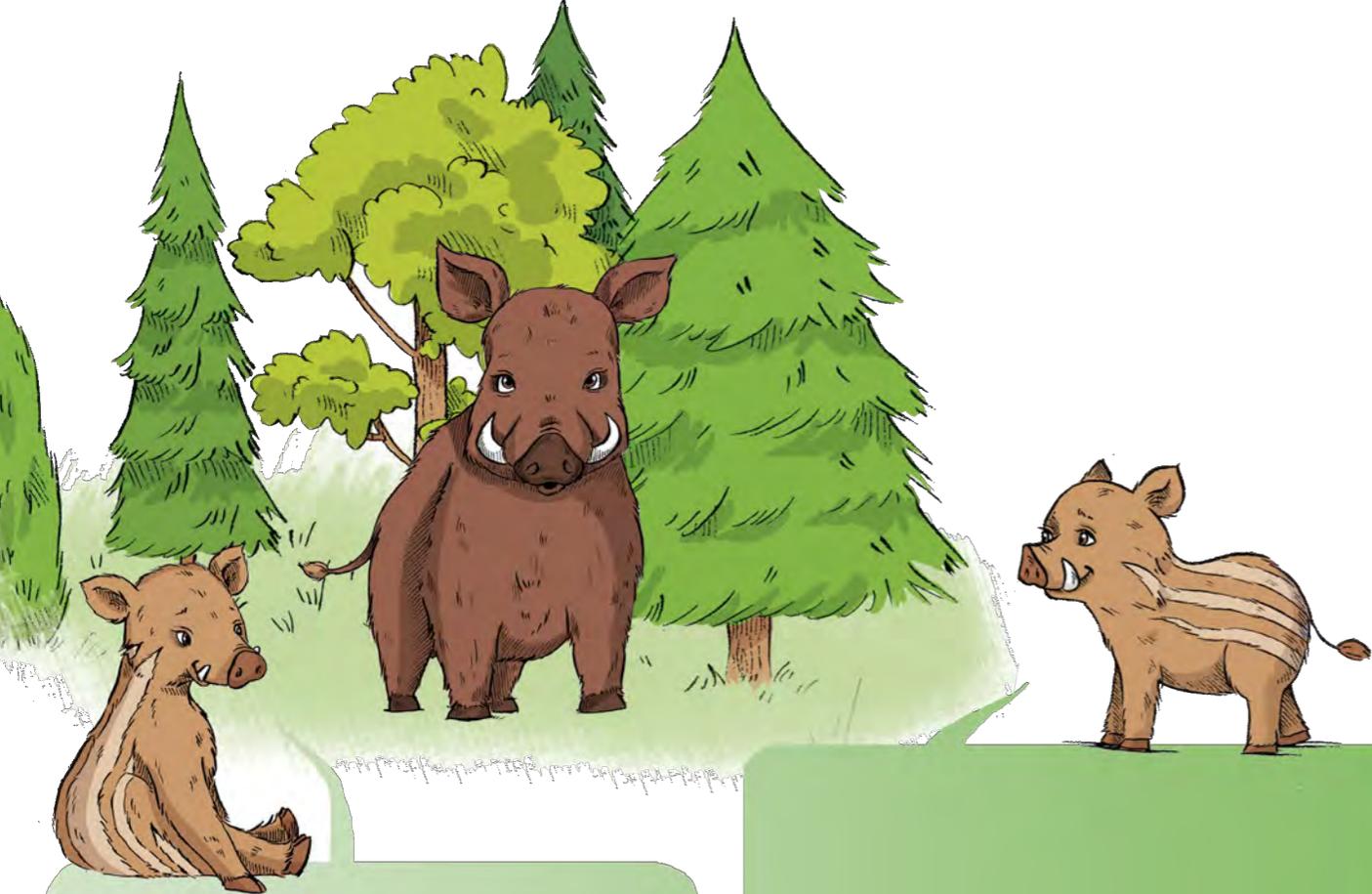
"Looking after your little brother and sister is not your job. That's a big responsibility for two young boars. We promise you that we will not leave you alone anymore."

From that day on, when Mummy and Daddy Boar left home, they took their four children with them, who were now more united than ever.



**Open the debate!**

Continue the story with the children!  
The questions on the next page will help you think about it.



What do you think of Olivia and Leo, the two youngest children?

What do you think of the behaviour of Eleanor and Hugo, the two older children, towards their brother and sister?

If a child has a brother or sister with a disability or disease, you can ask:

Do you think that this changes a lot in your everyday life? Any responsibilities? Any worries?

When you are with your brother or sister, do you feel that people look at you or act differently?

How does it make you feel to have a brother or sister with a disability or disease?

Does it make you feel angry, sad, ashamed or happy? Do you think it is unfair?

### About Siblings

Being the brother or sister of a child with a genetic disorder is quite an adventure in life. First of all, because the genetic disease takes up a lot of space in the family and sometimes you have to accept that you won't be able to have your mother and father for yourself. The hardest thing is to succeed in blaming only the disease and not your sick brother or sister, nor your parents, because no one is to blame. This situation is not always easy to cope with, and sometimes it feels good to be able to talk about it with other children who are going through the same thing. But having a sick brother or sister also teaches you to see life from a different perspective and understand things differently. When friends complain about little things, these brothers and sisters know what is really serious and they can be amazed at the very little things that sometimes go unnoticed: a smile, a new word, a tickle fight on the sofa... Loving this different brother or sister also shows us that we cannot judge people at first sight, but that we must take time to get to know someone. This tolerance and open-mindedness are also part of the adventure. This story was imagined by the "siblings" group of the genetics centre of the University Hospital Centre of Dijon, during a group session, in the presence of Mrs Lorraine Joly, psychologist.

### About the Author

Sonia Goerger is a medical secretary who has been welcoming and meeting many genetic patients for several years. This inspired her to create the "Children of Genetics" series of books for children.

The books in the series deal with the difficulties that patients may experience in their everyday lives, using simple words and endearing characters. To bring them to life, Sonia Goerger collaborated with Christine Juif, a clinical psychologist who assists patients with genetic diseases and their families during the diagnostic process.

### About the Illustrator

A graphic designer for several years, Elodie Garcia is an author and illustrator of children's books and comics. The delicacy of her line allows her to approach, in a gentle way, difficult subjects. By illustrating the "Children of Genetics" book series, she hopes to help families facing rare diseases.

## About the ARGAD Association

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

ARGAD engages in numerous activities:

- Improving reception and care conditions for patients with rare diseases in Burgundy, within the Genetics Centre of Dijon CHU;
- Raising awareness among health professionals in the Burgundy region, and among the general public regarding rare diseases;
- Contributing to a better and improved training of health professionals involved in rare diseases;
- And, supporting clinical and biological research activities in the field of genetic mutations associated with abnormalities in development and intellectual disabilities in Burgundy.

To support the ARGAD Association and its mission, visit: <http://www.translad.org/>



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When the two elder members of a family of wild boars have to look after two small boarlets affected by a disease that prevents them from seeing properly and having a sense of smell, things do not go as planned.

Together, they will have to deal with the difficult, unpredictable, and exciting aspects of being the brother or sister of a sick child.



“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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