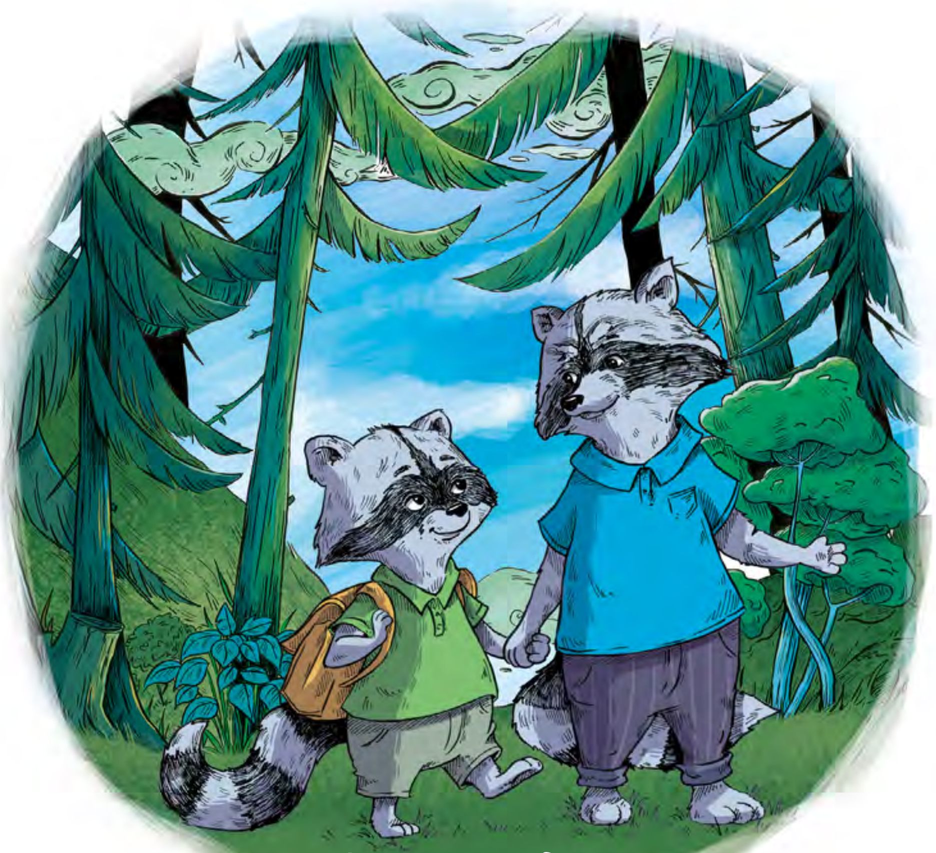
CHILDREN OF GENETICS

Sonia Goerger and Élodie Garcia



Moon, the Little Raccoon

ITHACA

European Reference Network
for rare or low prevalence complex diseases

Network
Intellectual Disability
and Congenital
Malformations (ERN ITHACA)

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BookLab

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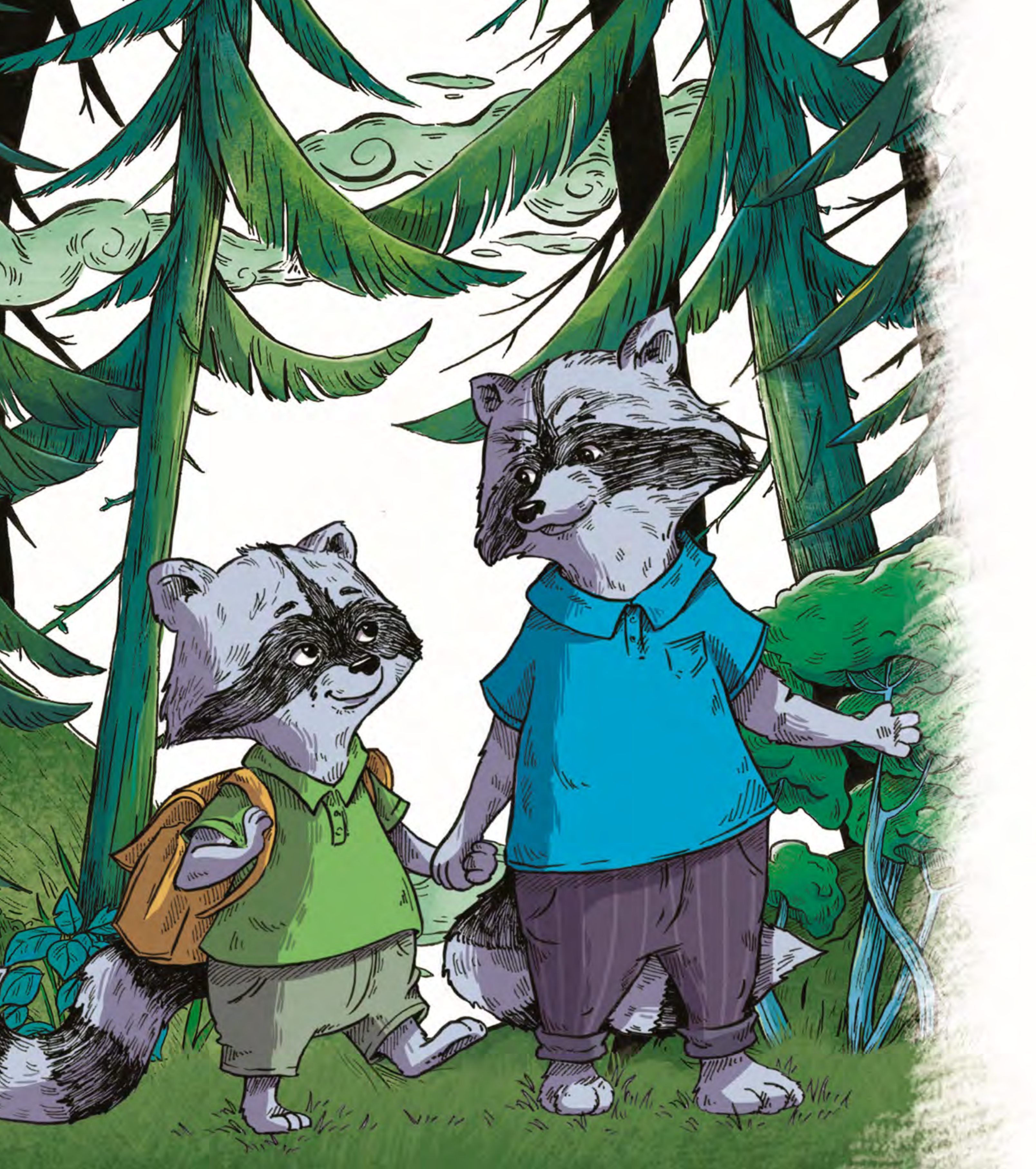
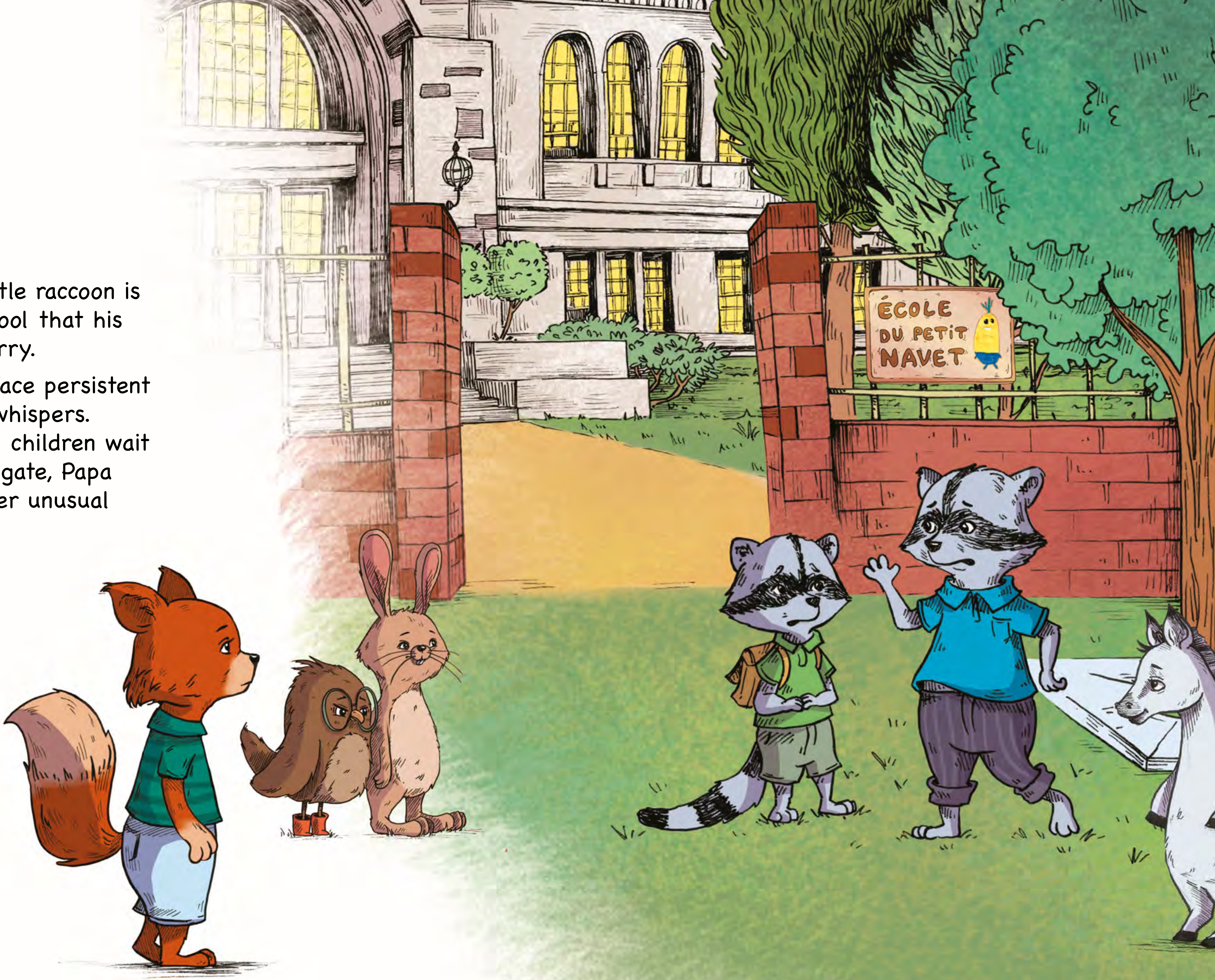


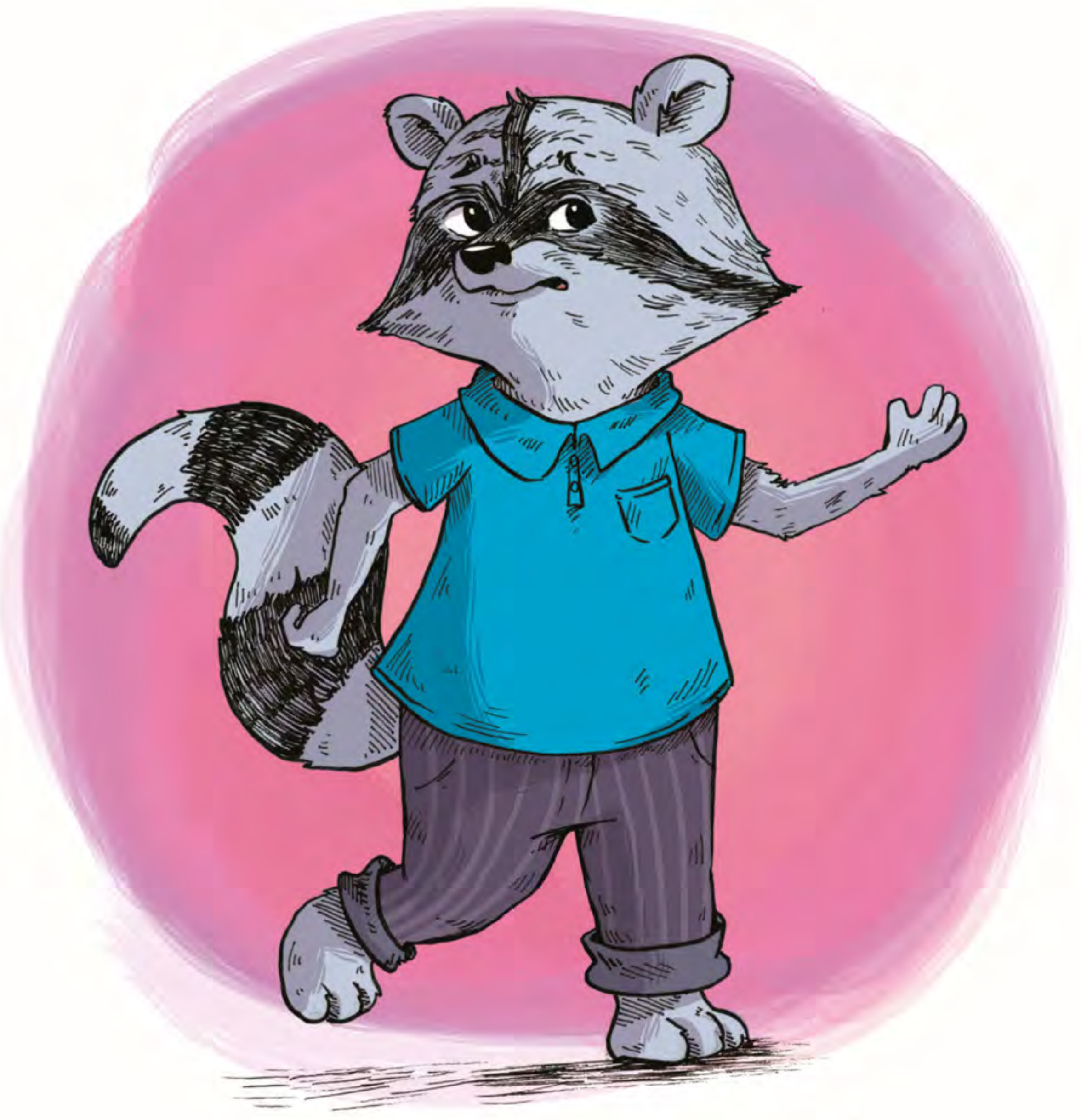
Like every morning, Moon,

the little raccoon, makes his way along the path that leads him to school, accompanied by his father, Papa Raccoon. It is a special moment together that Moon wouldn't change for anything in the world.

It is only when the little raccoon is about to arrive at school that his happiness turns to worry.

Every day, he has to face persistent stares and numerous whispers. While the parents and children wait in front of the school gate, Papa Raccoon begins a rather unusual dance.



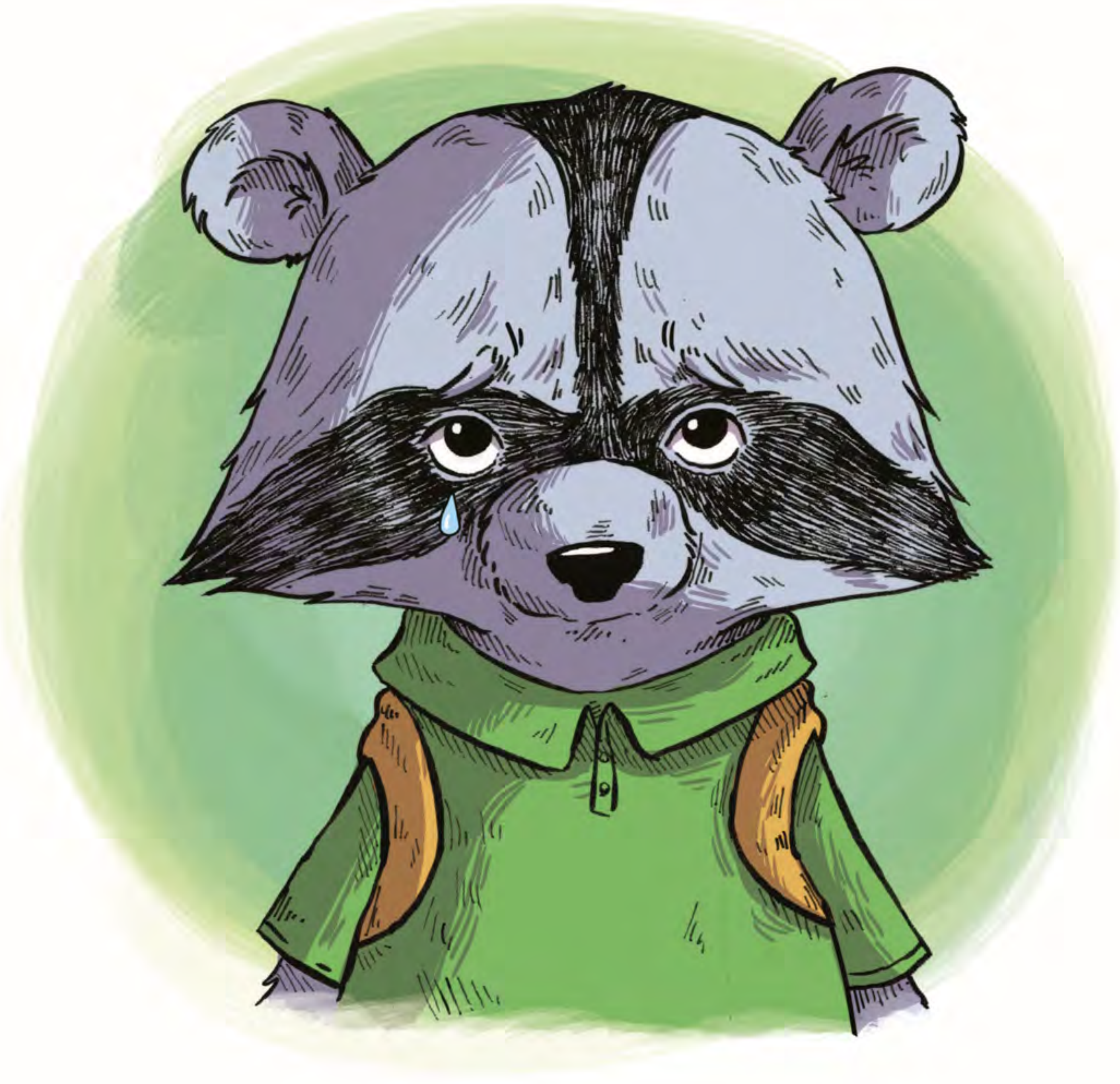


He makes big movements, staggers before straightening up, takes a few steps forward and then a few steps back, all while trying his best to stay on his two feet. Papa Raccoon also has a lot of trouble speaking and the words that come out of his mouth are hard to understand.

In front of this rather strange spectacle, the other parents judge him harshly.

> "Look at that, he can't even stand up straight ... He must be completely drunk," they whisper, staring at Papa Raccoon with nasty looks.

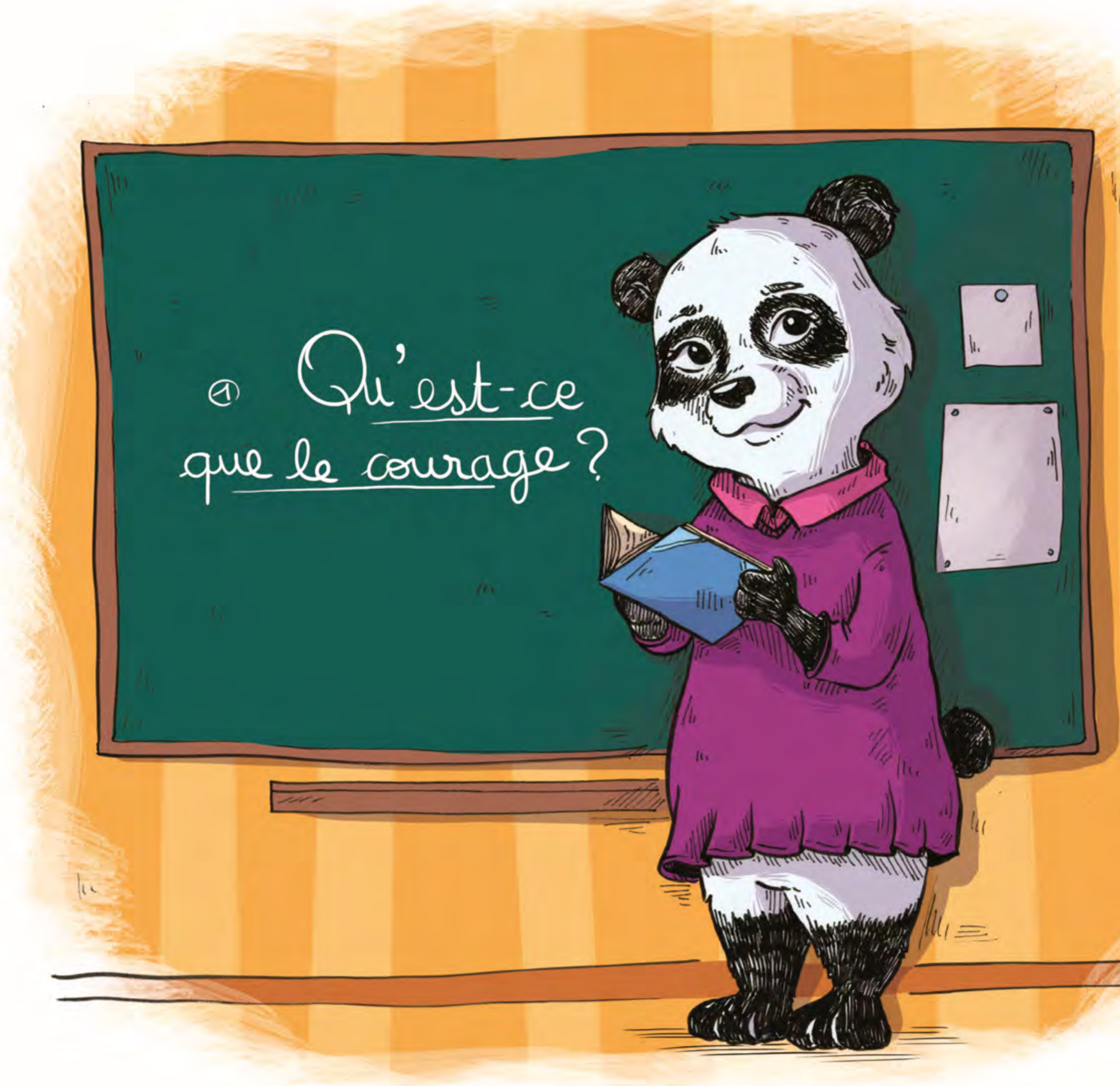
As for the kids, they point with their fingers and make fun of him.

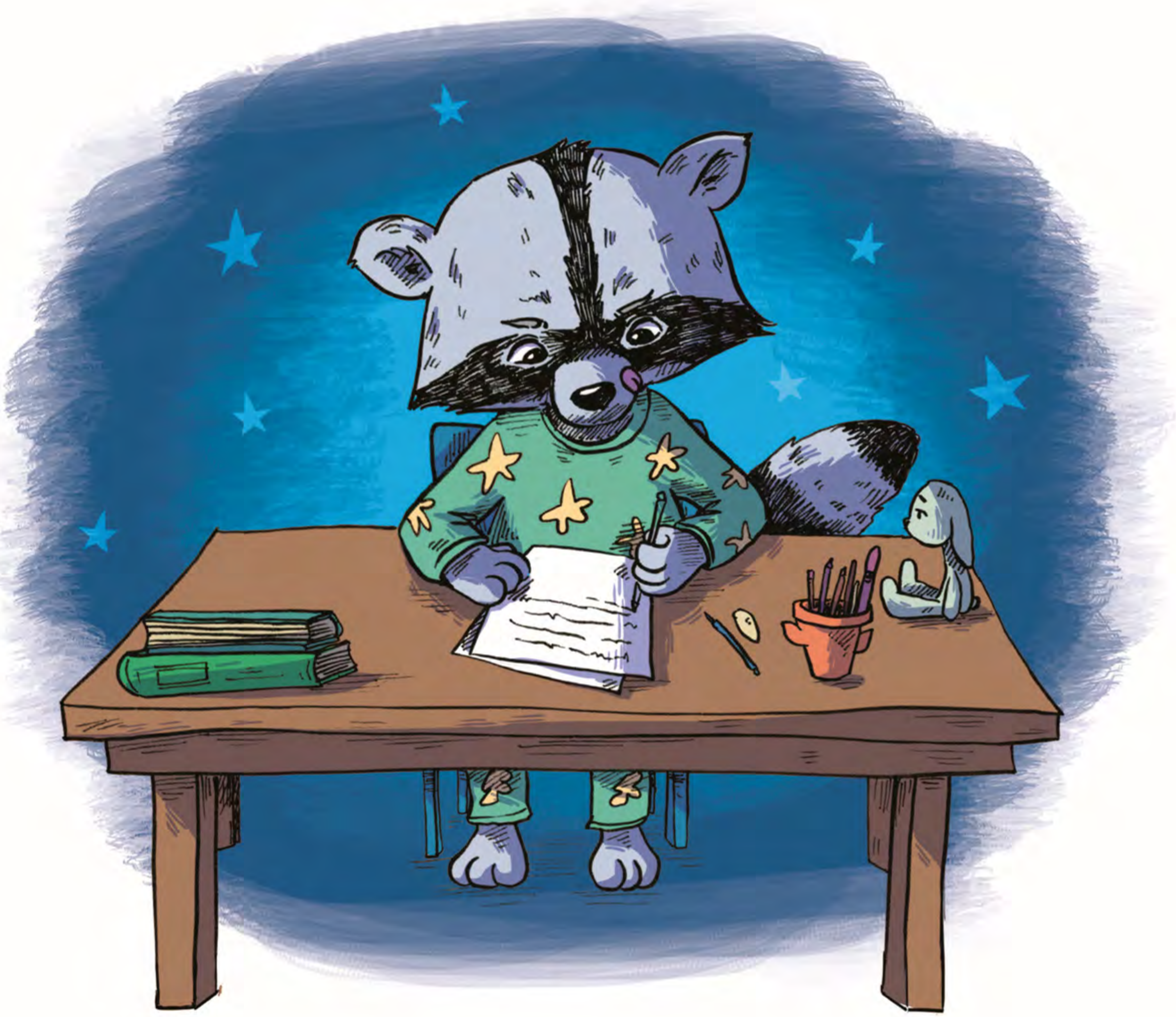


Nobody wants to approach or talk to Moon or his unusual dancing father. It is a situation that deeply saddens the young raccoon.

At the end of the day, before the school bell rings, Mrs. Panda, the teacher, announces the homework to be done.

> "For tomorrow, I would like you to prepare a presentation that you will give to the class on the topic of: What does bravery mean to you?"



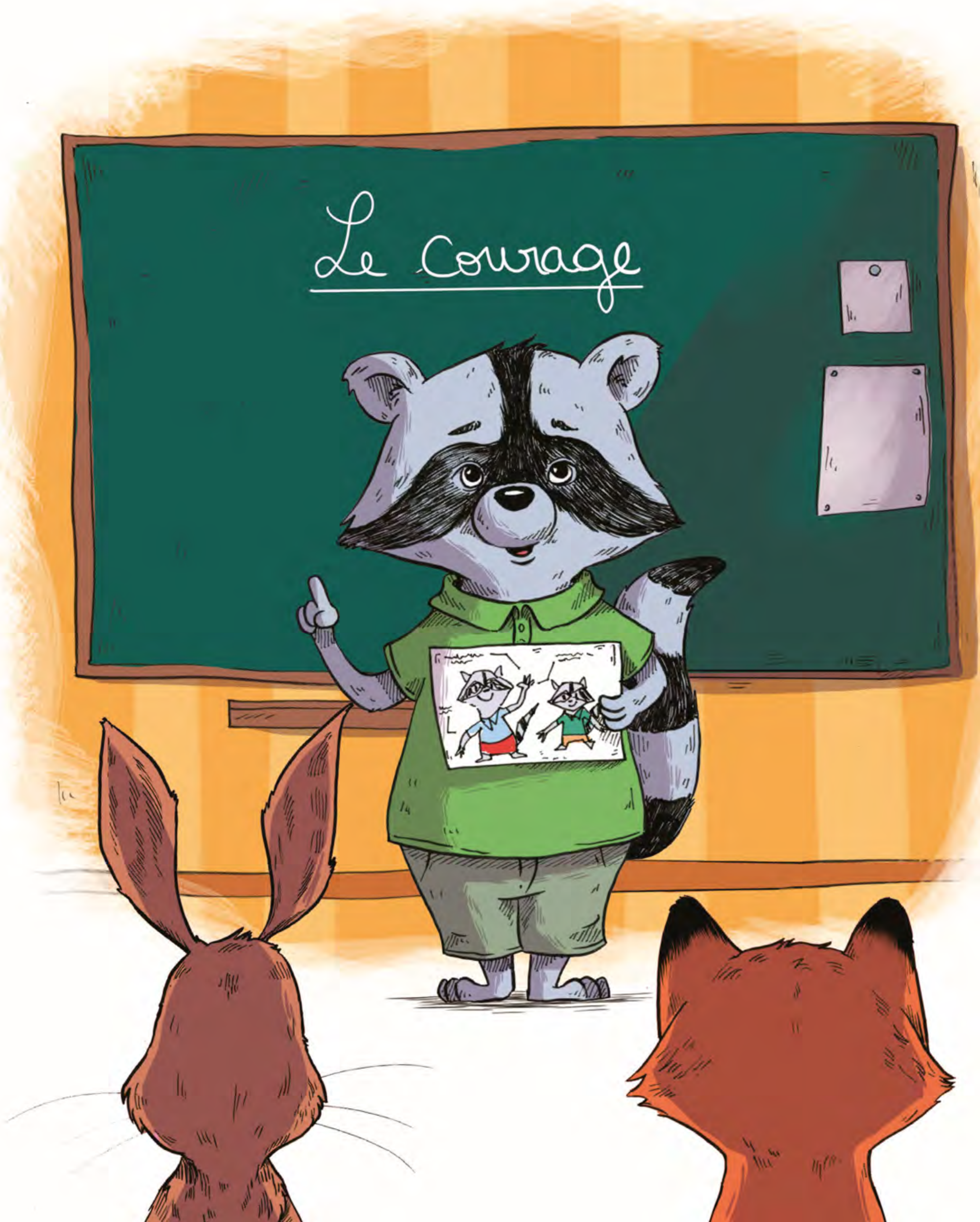


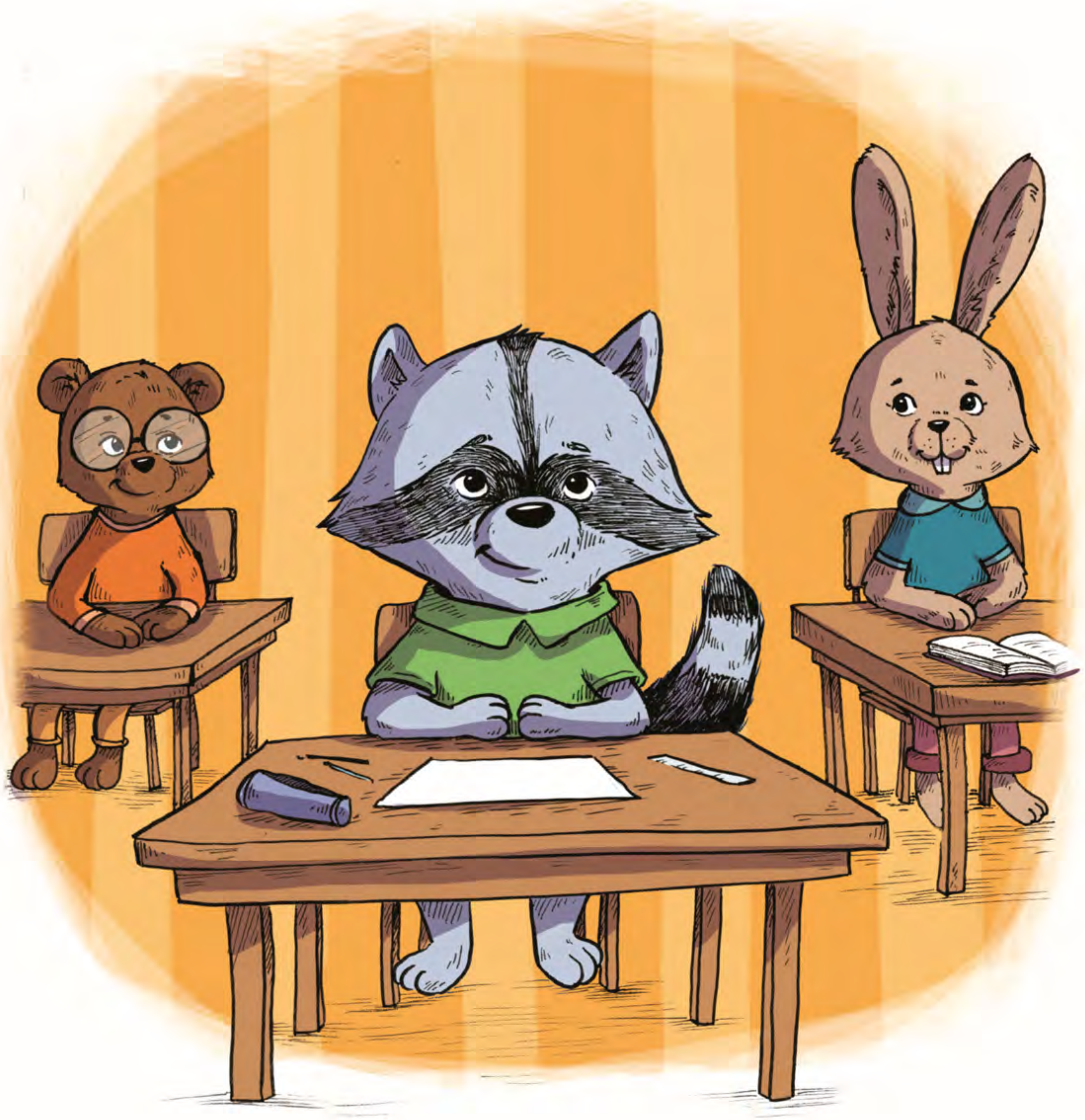
That evening, as soon as he gets home, Moon gets to work and starts writing. The words and sentences come to him easily.

The next say, though a little nervous, Moon is eager to share his presentation with his classmates. Standing in front of the class, the young raccoon takes a deep breath and starts to read his presentation.

He explains that his father has a rare disease, and it is because of this disease that he loses his balance, struggles to stand up and has trouble talking clearly. He shares how this incurable disease has changed their life and made things difficult, but also how his family remains strong and united against it.

> "I think that bravery is continuing to take your son to school every morning despite your disease, despite the effort that it requires, and despite the judgmental looks of others. Bravery is my dad!" Moon concludes.

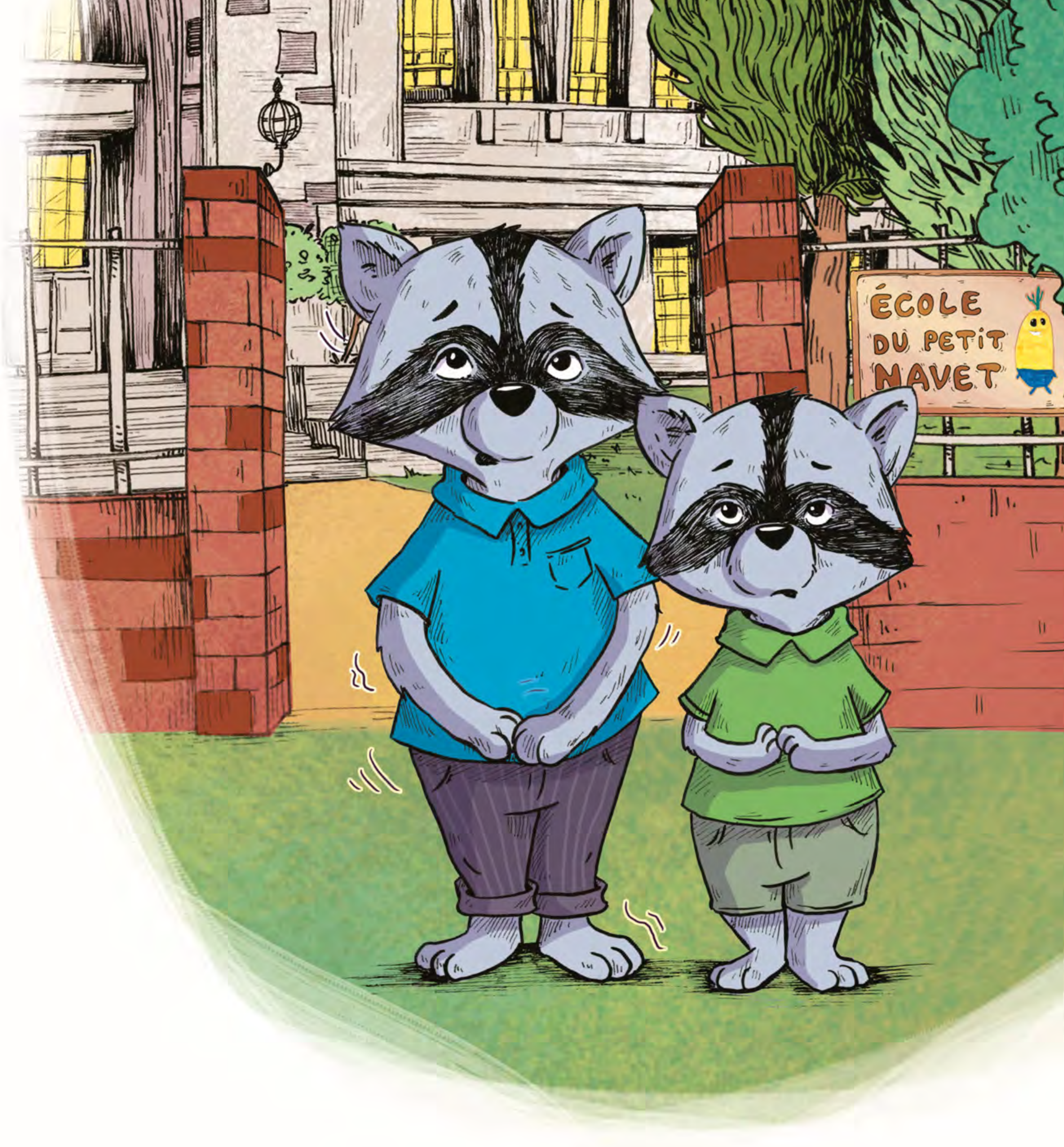


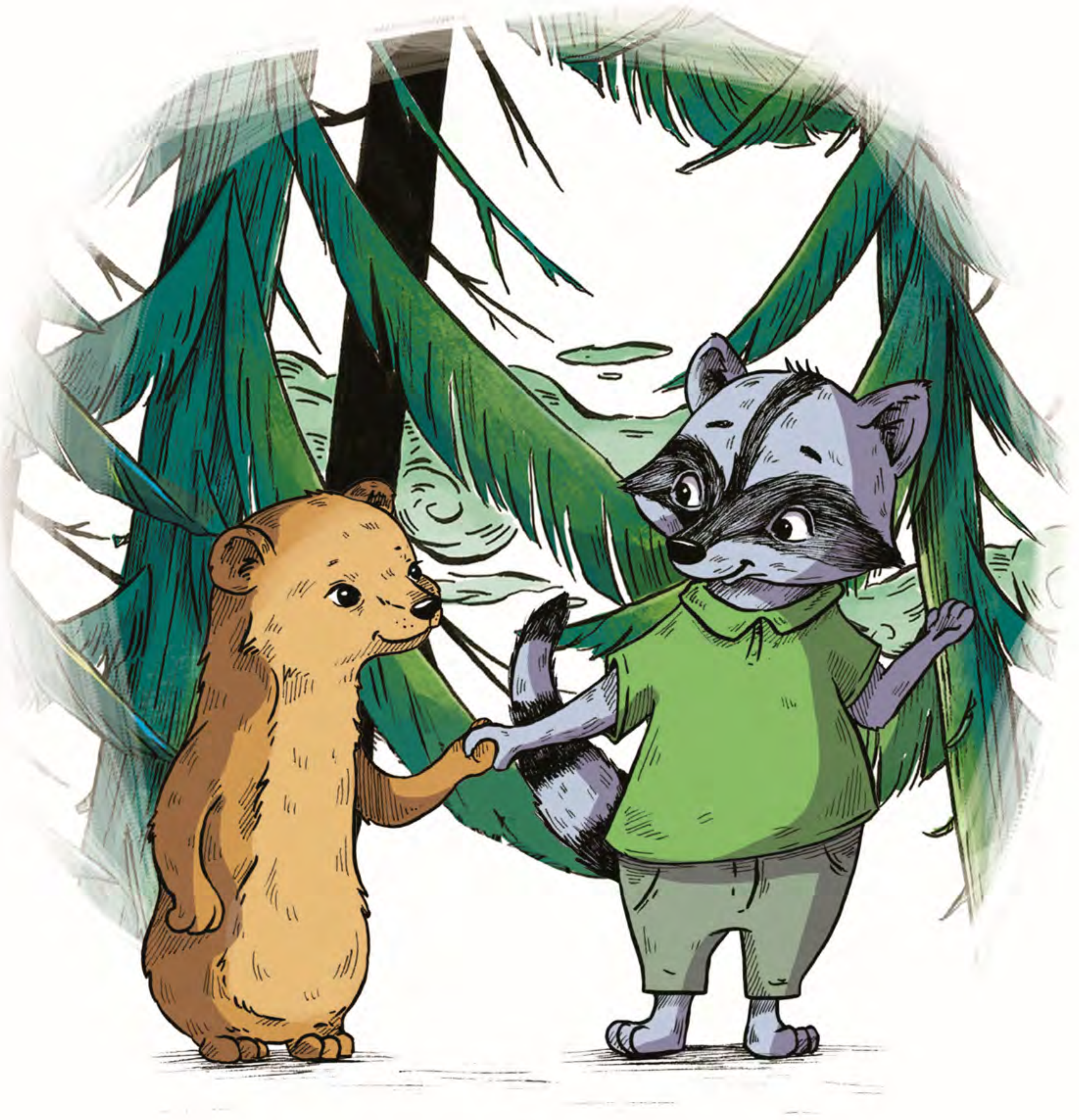


A heavy silence falls over the classroom. All of the students stare at Moon, stunned by what they have just learned. Mrs. Panda, very proud and deeply touched, smiles warmly at the little raccoon, with a hand placed over her heart.

Moon goes back to his seat, happy and relieved to have finally shared his experience. He secretly hopes that, thanks to his presentation, things might change.

The next morning, like every other day, Moon arrives at school accompanied by his father. The uncontrollable movements of Papa Raccoon soon return. Moon sighs and prepares himself for the usual flood of criticism and teasing. But that morning, what happens next is very different…





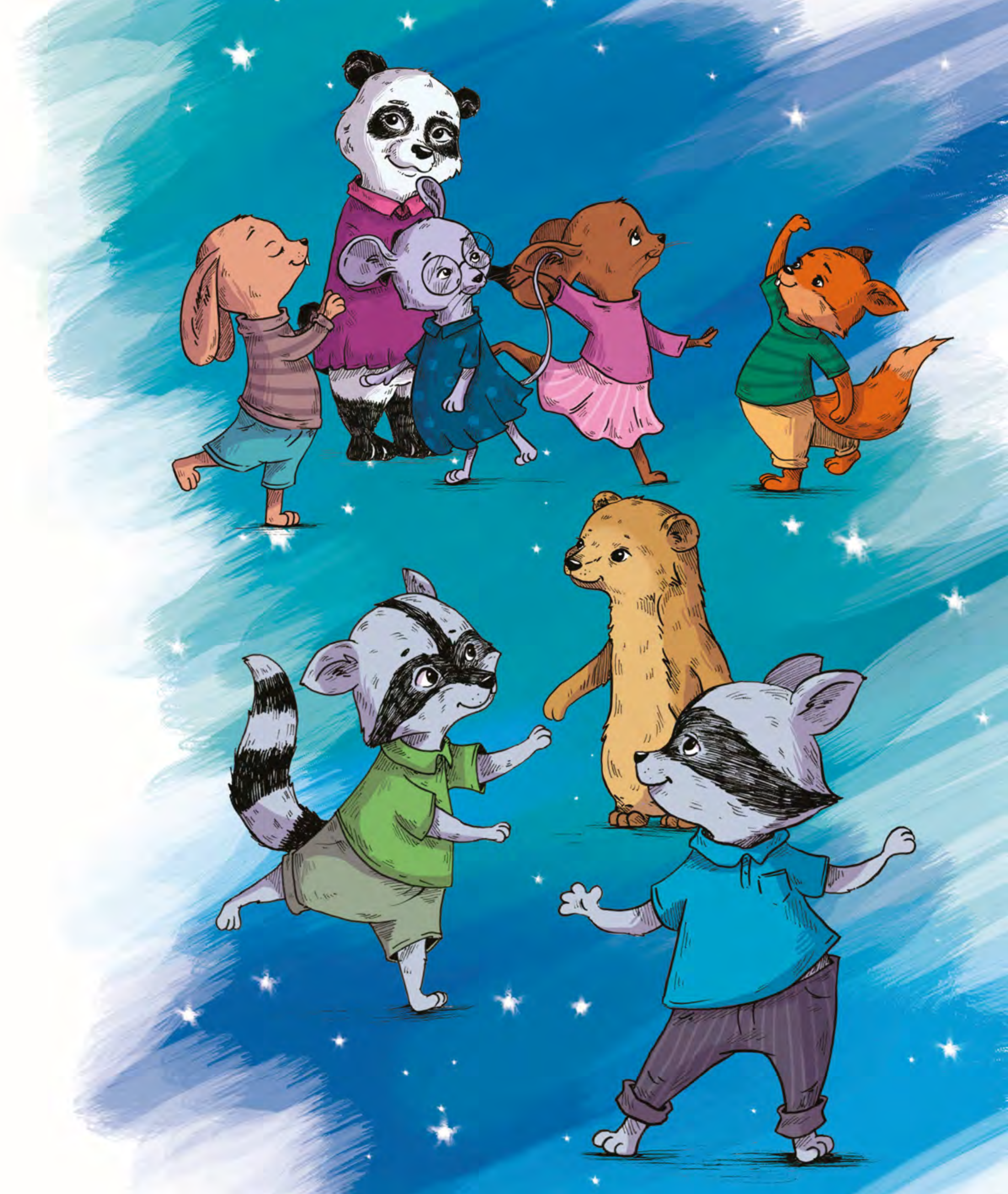
A young weasel approaches Moon and holds his hand out in a friendly manner. A child starts to dance, making large jerky movements and uncoordinated steps. A second child joins in, followed by a third! Then it is time for a mother and a father to join the dance. Before long, every parent and child, without exception, is participating in this strange but magnificent choreography!

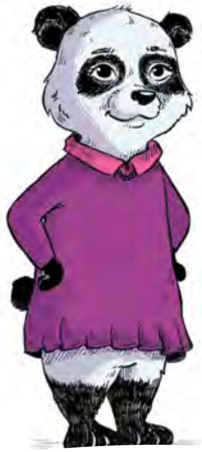
From that day forward, every morning, while waiting for the school gate to open, parents and children dance together in laughter and harmony, much to Moon's delight.

Papa Raccoon joins the others, his awkward movements blending perfectly, if only for an instant, in the most extraordinary of ballets.

Start the discussion!

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





About Moon

What do you think about Moon?

What emotions do you think Moon could have felt when he saw the reactions of others: anger, sadness, embarrassment, shame?

If you were Moon, how would you have felt? How would you have reacted?

Do you know someone who has difficulties walking or talking?

About Moon's Father

What do you think about Moon's father?

Do you think he is brave?

Did you think that Moon talking about his father's disease in front of his class was brave?

Do you remember a moment where you were brave?

About cerebellar ataxias

Cerebellar ataxias are a group of genetic neurodegenerative diseases. They are characterized by the development of a cerebellar syndrome which presents with walking, balance and coordination disturbances, as well as speech problems. These symptoms are similar to those of someone who is intoxicated, leading to unfair judgment from others and adding to the already complicated daily lives of patients. These problems are due to the involvement of the cerebellum, a small structure of the brain located at the back of the skull.

Very few cerebellar ataxias currently have a curative treatment available, but some, often associated with a metabolic etiology, are amenable to targeted therapies that can halt the progression of the disease or even improve symptoms. Functional rehabilitation, as well as medical (neurologist, rehabilitation physician, primary care physician), paramedical (physiotherapist, occupational therapist, speech-language therapist), psychological and social support are essential for patients affected by these diseases.

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/

About Fondation Ipsen BookLab

At the service of the general interest, working towards an equitable society, the Fondation Ipsen BookLab publishes and distributes books free of charge, primarily to schools and associations. Through collaborations between experts, artists, authors and children, our publications, for all ages and in a variety of languages, focus on the education and awareness of issues related to health, disability and rare diseases. Discover our complete catalog online at **https://www.fondation-ipsen.org/books/**.

Book # 10.11
Have your say!

ISBN: 978-2-38427-241-9 (printed book_French version)/ 978-2-38427-242-6 (ePub_French version)/
978-2-38427-243-3 (POD _English version)/ 978-2-38427-244-0 (ePub_English version)/
978-2-38427-245-7 (POD_Spanish version)/ 978-2-38427-246-4 (ePub_Spanish version)/
978-2-38427-249-5 (POD_Chinese version)/ 978-2-38427-250-1 (ePub_Chinese version)/
978-2-38427-247-1 (POD_Ukrainian version)/ 978-2-38427-248-8 (ePub_Ukrainian version)

Fondation Ipsen is under the aegis of Fondation de France
www.fondation-ipsen.org

Text: Sonia Goerger (with the kind collaboration of Christine Juif)
Illustrations: Elodie Garcia
Scientific editing: Association for Research in Genetics and Support for Families and Professionals in Dijon-Bourgogne (ARGAD - Association de Recherche en Génétique et d'Accompagnement des familles et professionnels de Dijon-Bourgogne)
Translation: Natasha Barr – www.caretently.com
Editorial direction: Céline Colombier-Maffre

First published in French, in January 2025

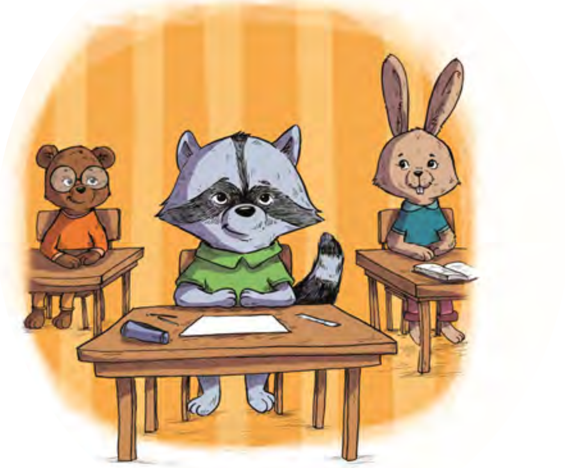
Act No 49-956 of 16 July 1949 on publications for young people,
amended by Act No. 2011-525 of 17 May 2011.
Legal deposit: January 2025

Print on demand, by Fondation Ipsen, Paris, France

ePub Conversion: www.flexedo.com

Not for sale - free book

Every morning, Moon, the little raccoon, faces mockery due to his father's awkward movements, which are caused by a rare disease. But a presentation about bravery will change everything. A collective dance is born, transforming differences into solidarity. A moving story about acceptance, love, and the strength of family bonds.



"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
www.fondation-ipsen.org

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