

CHILDREN OF GENETICS

Sonia Goerger and Élodie Garcia



Merlin, the Little Feline



European
Reference
Network
for rare or low prevalence
complex diseases

Network
Intellectual Disability
and Congenital
Malformations (ERN ITHACA)



Sonia Goerger and Élodie Garcia

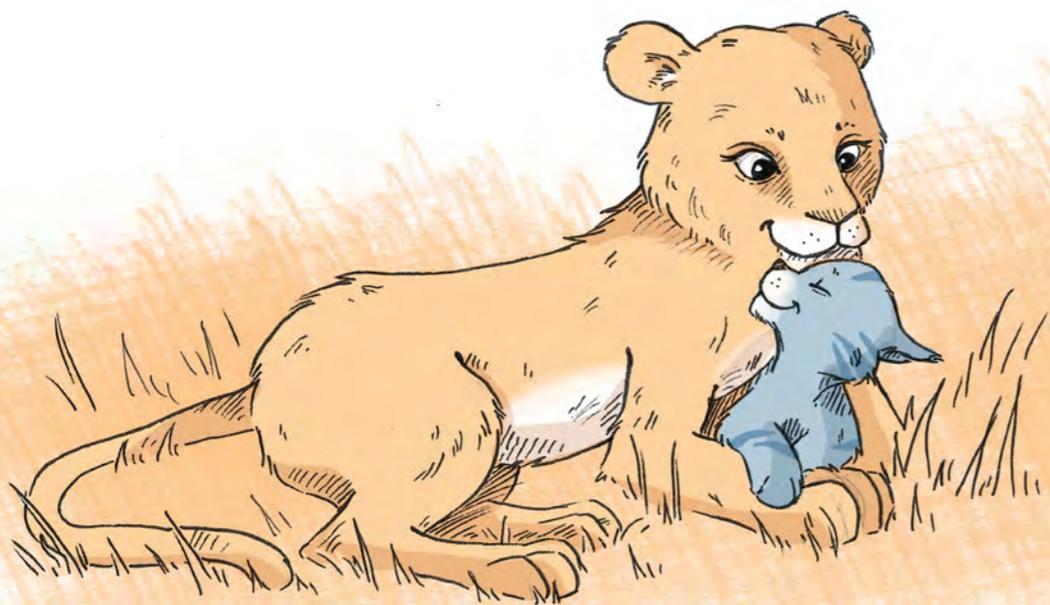
Merlin, the Little Feline

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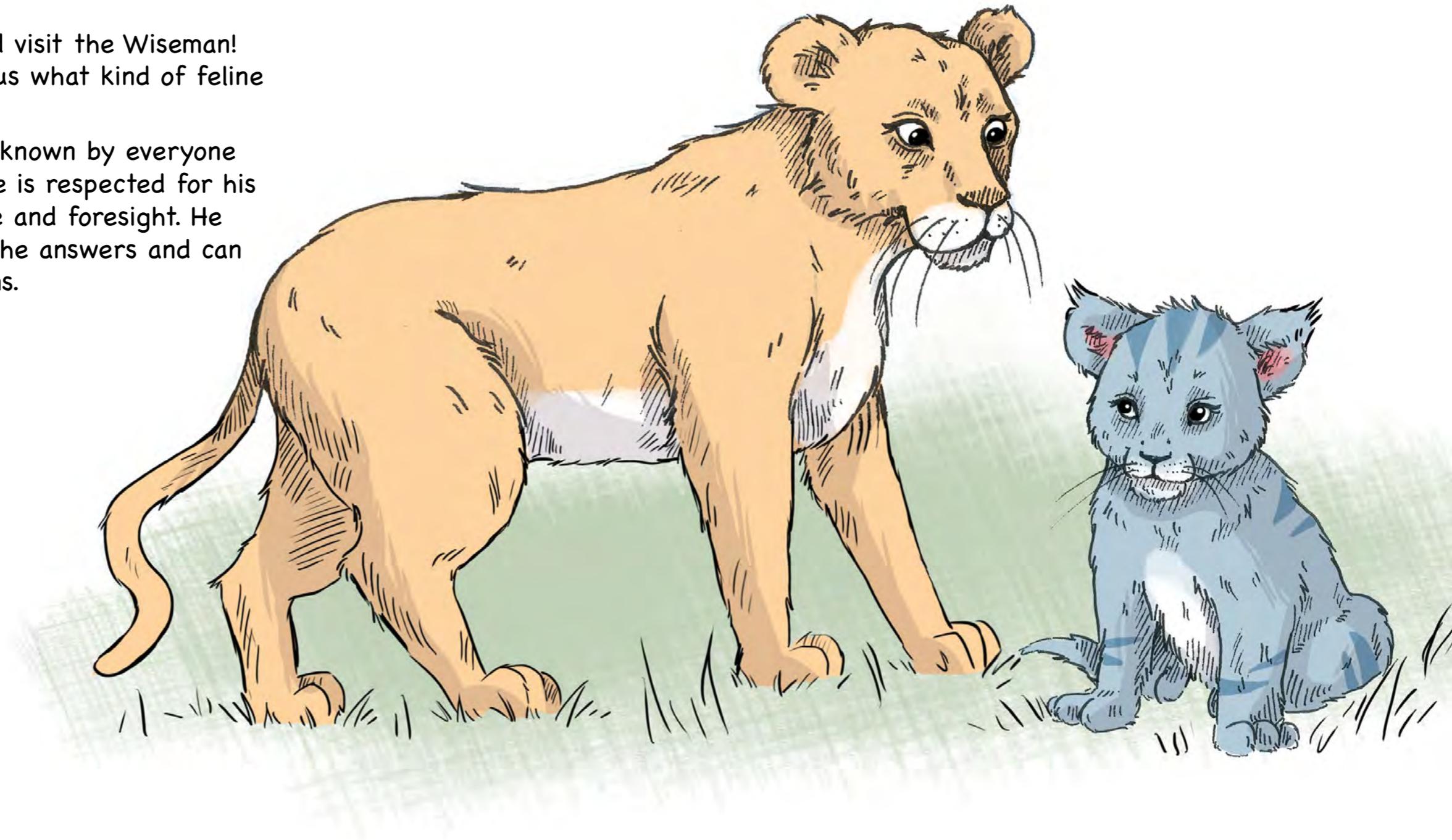
Merlin is a cute feline. He lives in a South African village with his mother, a beautiful honey-coloured lioness. Merlin's mother loves him very much. But Merlin does not look like an ordinary lion cub! He doesn't even look like an ordinary cat! He gets lots of unfriendly looks and mean comments from others, because he is different.



One day, Mother Lioness says to Merlin:

“Let’s go and visit the Wiseman!
He will tell us what kind of feline
you are!”

The Wiseman is known by everyone
in the village. He is respected for his
great knowledge and foresight. He
usually has all the answers and can
fix most problems.





The Wiseman, an old monkey, looks at Merlin carefully. He is a little puzzled. He pauses to think, flipping through one of his many books. He examines Merlin again. After a few minutes he says:

“I don’t know! I don’t have an answer. My advice is to travel. Explore other villages and countries. Go and meet other species. You will eventually find some help.”



Mother Lioness and Merlin set off for cheetah village a few miles away.

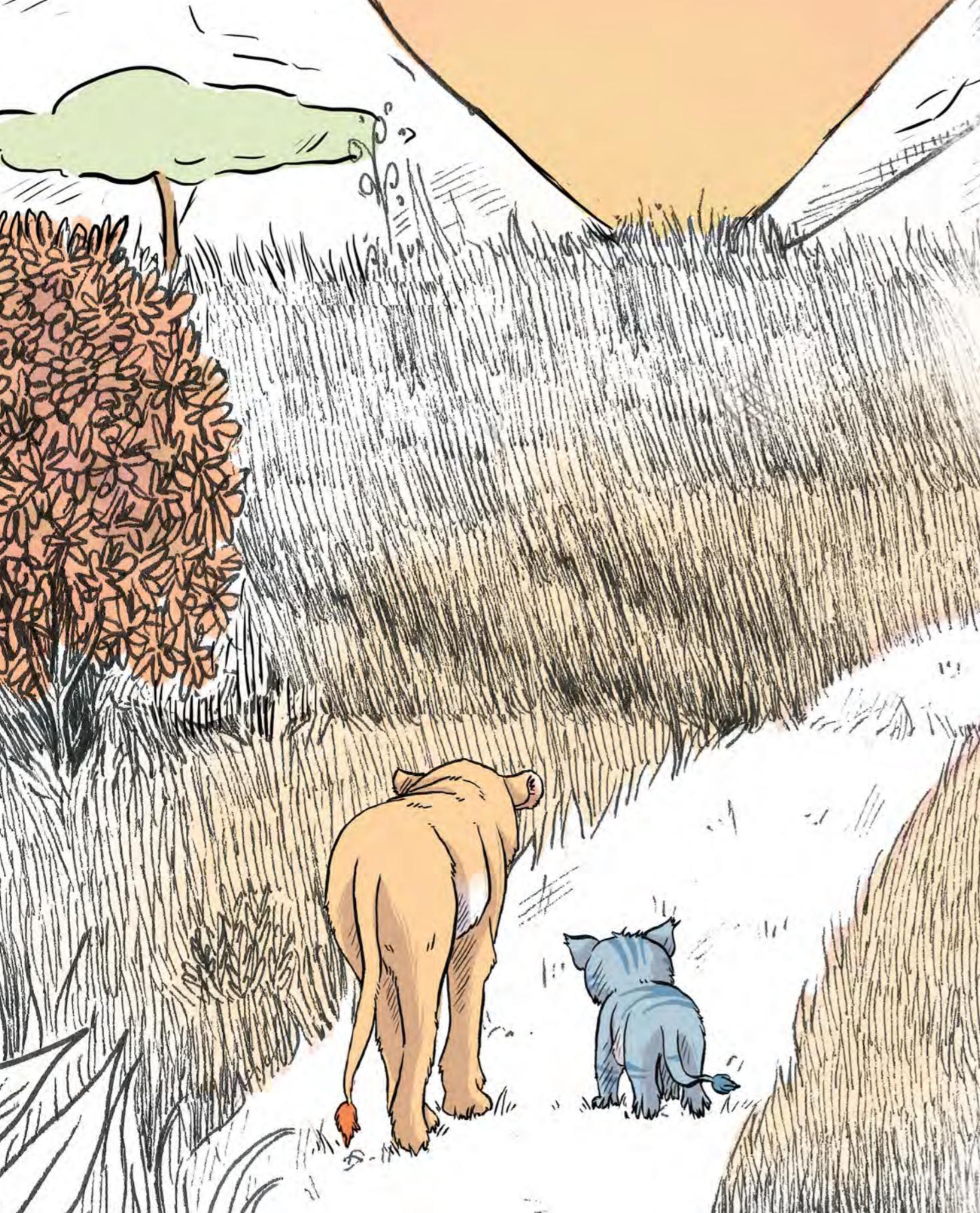
"Looking for something?" asks a young cheetah, curious about the two strangers.

"I came to see if you had a cheetah in your village that looks like my son," replies Mother Lioness hopefully.

The cheetah, who believes he is better than everyone else, looks at Merlin and exclaims:

"Definitely not! You can see that he has no spots! Your son is not a cheetah!"





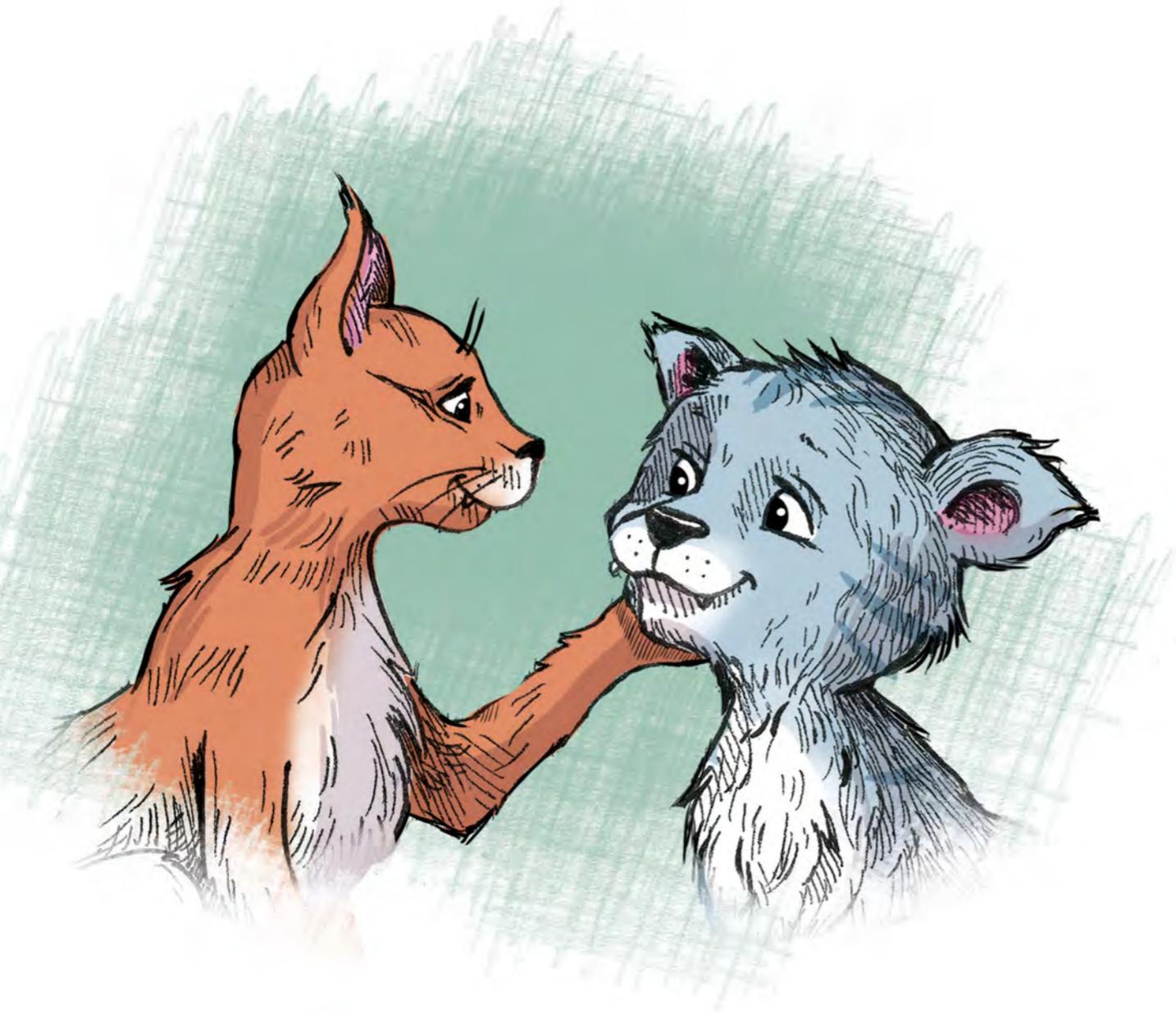
Mother Lioness and Merlin set off again. This time they travel to the caracal village. The journey is long. They are very tired. Mother Lioness thinks about giving up. But she can't. She needs to find out why Merlin is different. She wants Merlin to grow up with other felines that are the same as him. After many days of walking, they arrive at caracal village.

"Hello, I am sorry to bother you. I'm looking for a feline that looks like my son," Mother Lioness says.

Mother Caracal looks at Merlin for a long time. She says in a soft, kind voice:

"He does have pointy ears like us, but that is all. He is not part of our species."





Mother Caracal looks at Merlin and smiles thoughtfully.

“You are one of a kind. That is very hard to find! You are truly special!”

Her words are heartfelt and caring. Mother Lioness feels comforted. Mother Caracal is right, she thinks. Merlin is one of a kind. After they have said goodbye, Mother Lioness and Merlin continue their journey.



Mother Lioness searches for an answer for days, weeks, and months. They travel from village to village, country to country. Every feline has the same answer: Merlin is not one of theirs.

Merlin is not a leopard. He is not a serval cat. He is not even an African wildcat. Mother Lioness doesn't know where to go or what to do. So, she wanders around the African bush with Merlin, hoping that someone might help them.



One morning, as mother and son are resting at the foot of a tree, a miracle happens. A rhinoceros approaches them slowly.

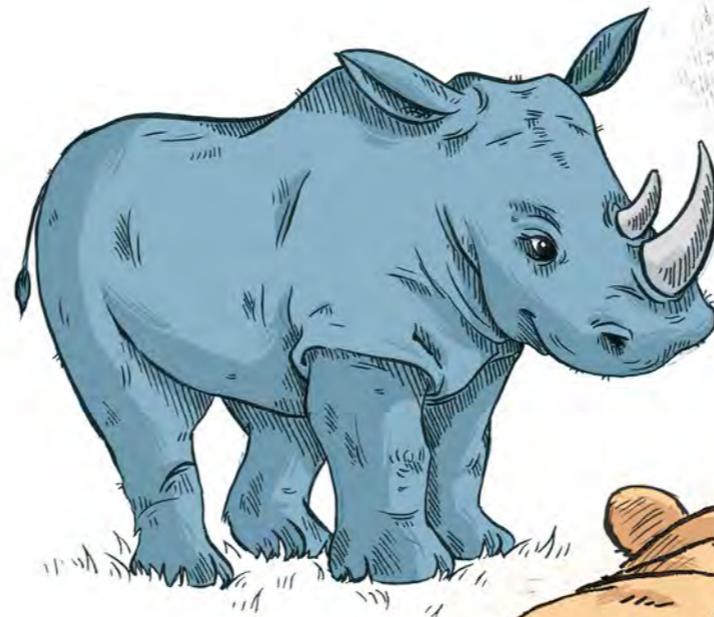
"Hello! I've heard about both of you and your amazing story. I think I can help," announces the rhinoceros.

Mother Lioness and Merlin follow him to his village. There, they arrive at a shelter.

The friendly rhinoceros is the owner of the shelter. There are 15 abandoned animals living in the shelter. The rhinoceros is looking after all of them.

“Follow me. I want to introduce you to somebody!” says the rhinoceros.

To her great surprise, Mother Lioness discovers a young feline who looks just the same as Merlin!





This feline is a bit older than Merlin. His coat is also charcoal grey, and he also has pointed ears. He also has difficulty running. Just like Merlin. He was separated from his pride a few years back when he couldn't keep up with them. He is doing very well at the shelter.

It has been a long and tiring journey. But Mother Lioness has finally found what she has been searching for. Now she understands and knows: Merlin is one of a kind. He is unique. And he will remain this way for the rest of his life. Except, he is not alone.



About Diagnostic Errancy

Diagnostic errancy refers to the period during which a patient waits for a diagnosis. It can last particularly long in the case of rare diseases that affect 3 million people in France. Diagnostic errancy can be the cause of real suffering for patients, and their families, who often feel neither heard nor understood. Private, social, or professional life can be severely affected, leading to isolation.

The role of Reference Centres and Competence Centres is essential. As pillars in the fight against diagnostic errancy, these centres play a key role in confirming the diagnosis, which they provide in most cases. Identifying the genetic cause of a rare disease is an essential step in setting up appropriate medical follow-up, preventing complications, developing personalised therapeutic strategies, and providing genetic counselling. The scientific advances in the field of genetic analysis in recent years, and in particular, the arrival of high-throughput exome and genome sequencing, have made it possible to diagnose many patients who have been in diagnostic limbo, sometimes for years, and remain a real hope for all patients who are still searching for a diagnosis.

About the Author

Medical secretary, Sonia Goerger, has been welcoming and meeting numerous patients dealing with genetics for many years. This interaction inspired her to create this series of books on *Children of Genetics*.

The books within this collection address challenges these patients may face daily, in simple terms and with endearing characters.

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:

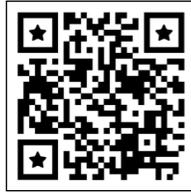
- Improving reception and care conditions for patients with rare diseases in Burgundy, within the Genetics Centre of Dijon CHU;
- Raising awareness among health professionals in the Burgundy region, and among the general public regarding rare diseases;
- Contributing to a better and improved training 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/>



About Fondation Ipsen BookLab

Truthful transmission of science to the public is complex because scientific information is often technical and leads to the diffusion of inaccurate information. In 2018, Fondation Ipsen established BookLab to address this need. BookLab publications are created through a collaborative process between scientists, doctors, artists, authors, and children. Existing in paper and electronic formats, and in several languages, BookLab provides books to more than 50 countries, for people of all ages and cultures. Fondation Ipsen BookLab publications are provided free of charge to schools, libraries and people living in precarious situations. Join us! Access and share our books by visiting www.fondation-ipsen.org.



Book # 10.3

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Not for sale - free book

Diagnostic errancy is devastating
for individuals with rare diseases
and their families.

To understand her son's differences,
Mother Lioness relentlessly travels
the African savannah.



“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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