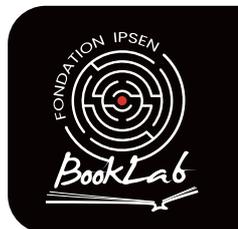


Sonia Goerger and Élodie Garcia



Arno,
the Little Sparrow

CHILDREN OF GENETICS

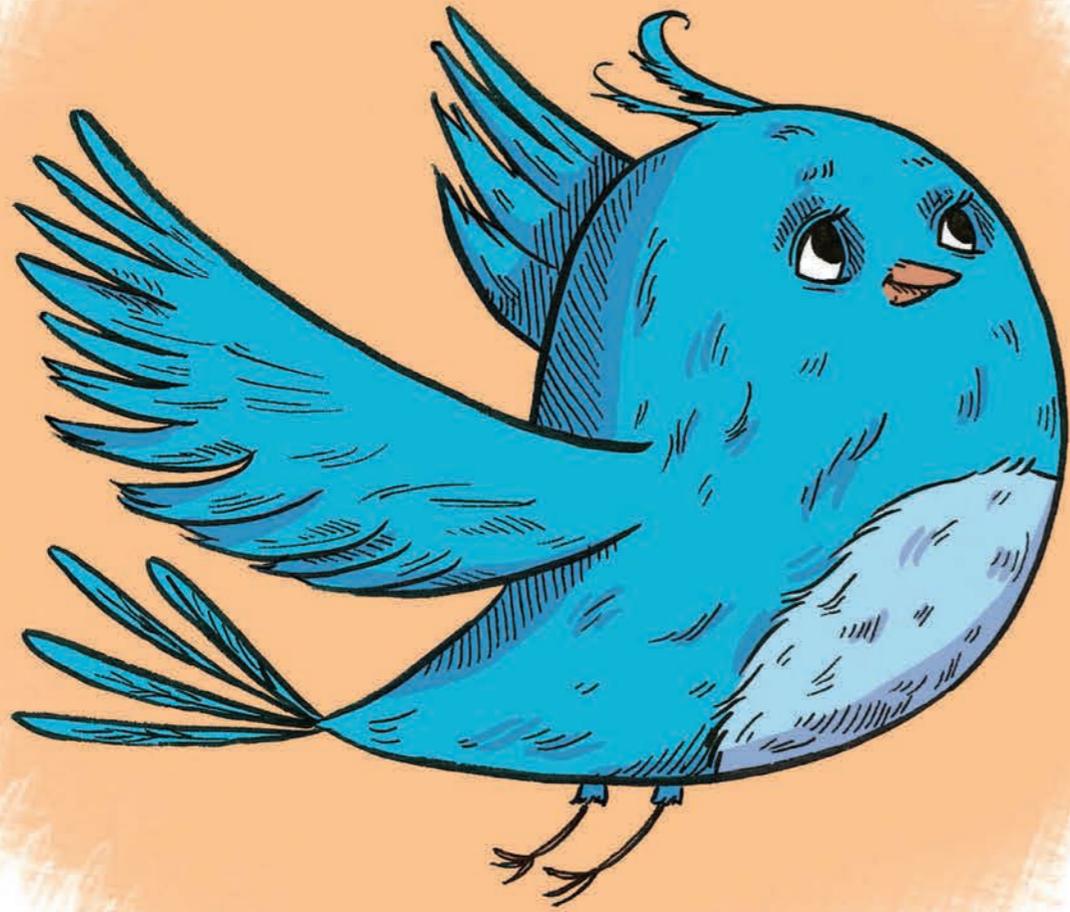


Sonia Goerger and Élodie Garcia

*Arno,
the Little Sparrow*

LES ENFANTS DE LA GÉNÉTIQUE





Arno is an adorable little sparrow.
Like all the little sparrows of his
age, he is full of energy.

But one day, the wind came and told
Arno's parents some terrible news.



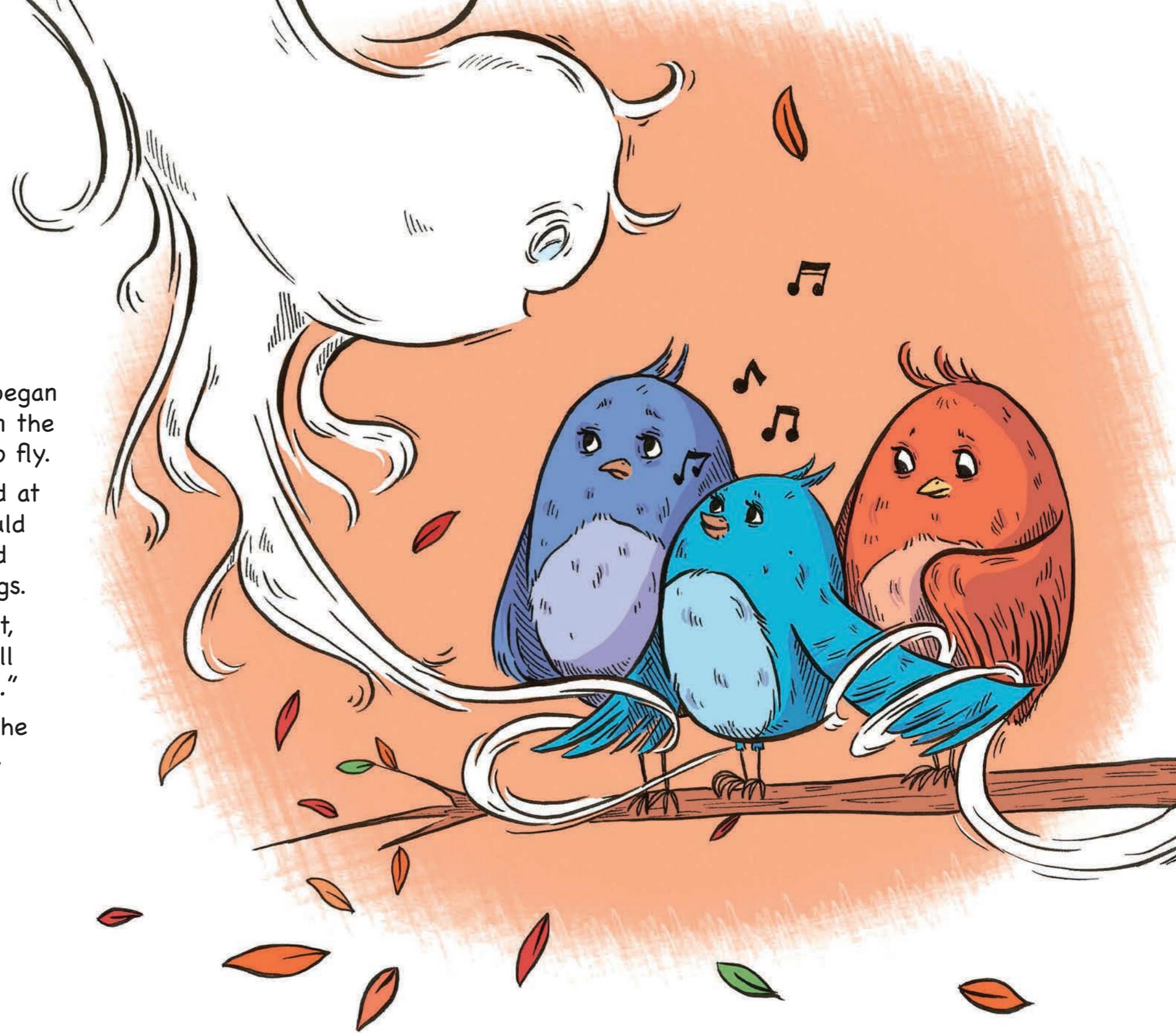


Arno has a disease with a frightening and unpronounceable name, which will take away the beautiful things he has acquired over the years.

One autumn morning, as leaves began to fall, Arno's disease knocked on the door and took away his ability to fly. The little sparrow's parents cried at the thought that their child would soon be unable to take flight and caress the blue sky with his wings.

"It's not fair, but don't forget, the wind whispered, Arno still has plenty of other abilities..."

And as if to echo the words of the wind, Arno began to sing happily, with a smile on his face.





One cold winter night, as snow covered the ground, Arno's disease knocked on the door and stole his ability to sing.

Arno's parents cried at the thought that soon they would not be able to hear their beloved son scream and sing at the top of his voice.

"It's not fair, but don't forget, the wind whispered, Arno still has plenty of other abilities..."

And as if to echo the words of the wind, Arno looked at his parents tenderly, with a smile on his face.

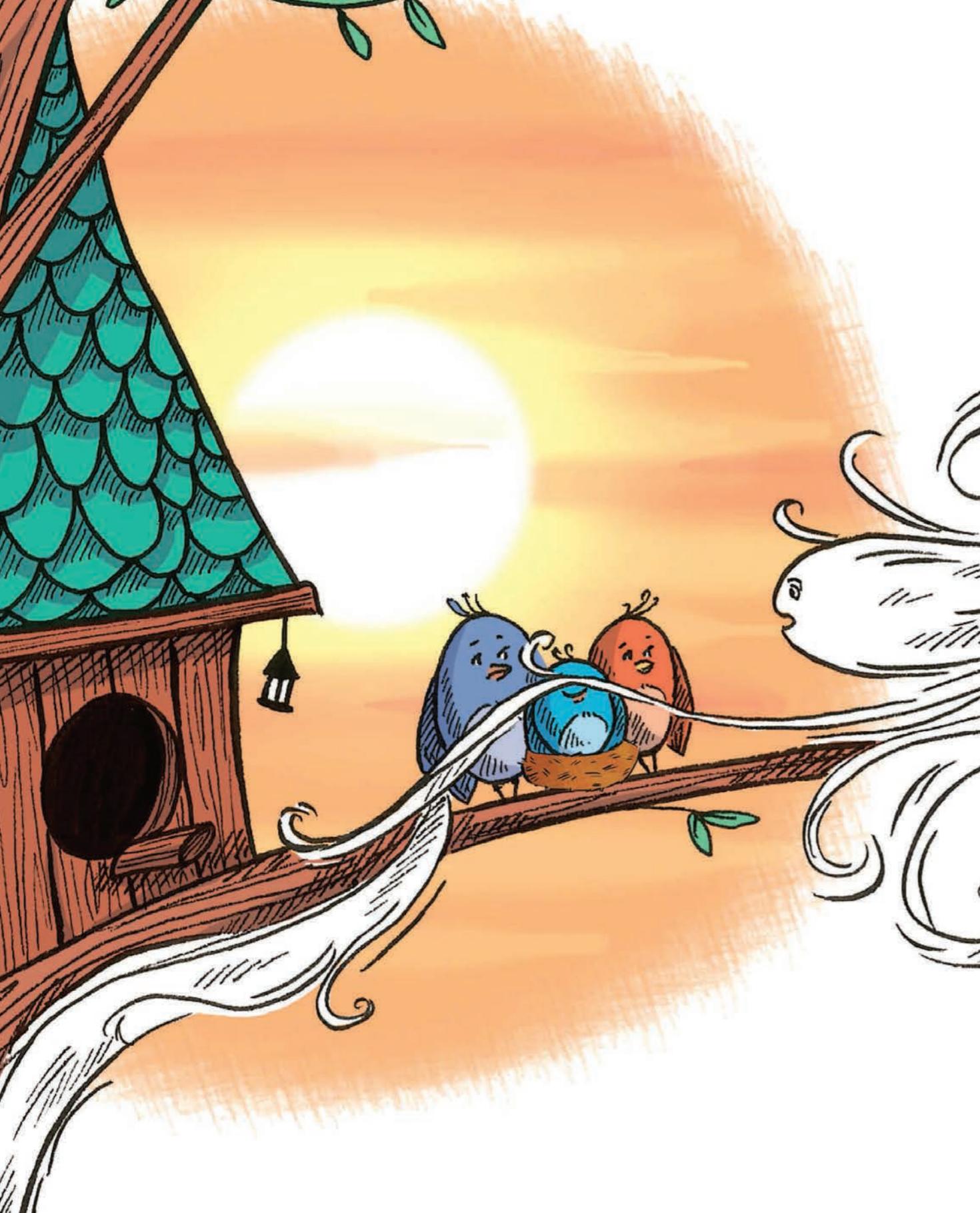
One spring afternoon, as flowering trees began to bloom, Arno's disease knocked on the door and took away his ability to see.

The little bird's parents cried at the thought that Arno would soon be unable to admire the beautiful colours around him.

"It's not fair, but don't forget, the wind whispered, Arno still has plenty of other abilities..."

And as if to echo the words of the wind, Arno kept an ear out to show his parents that he was listening to them, with a smile on his face.





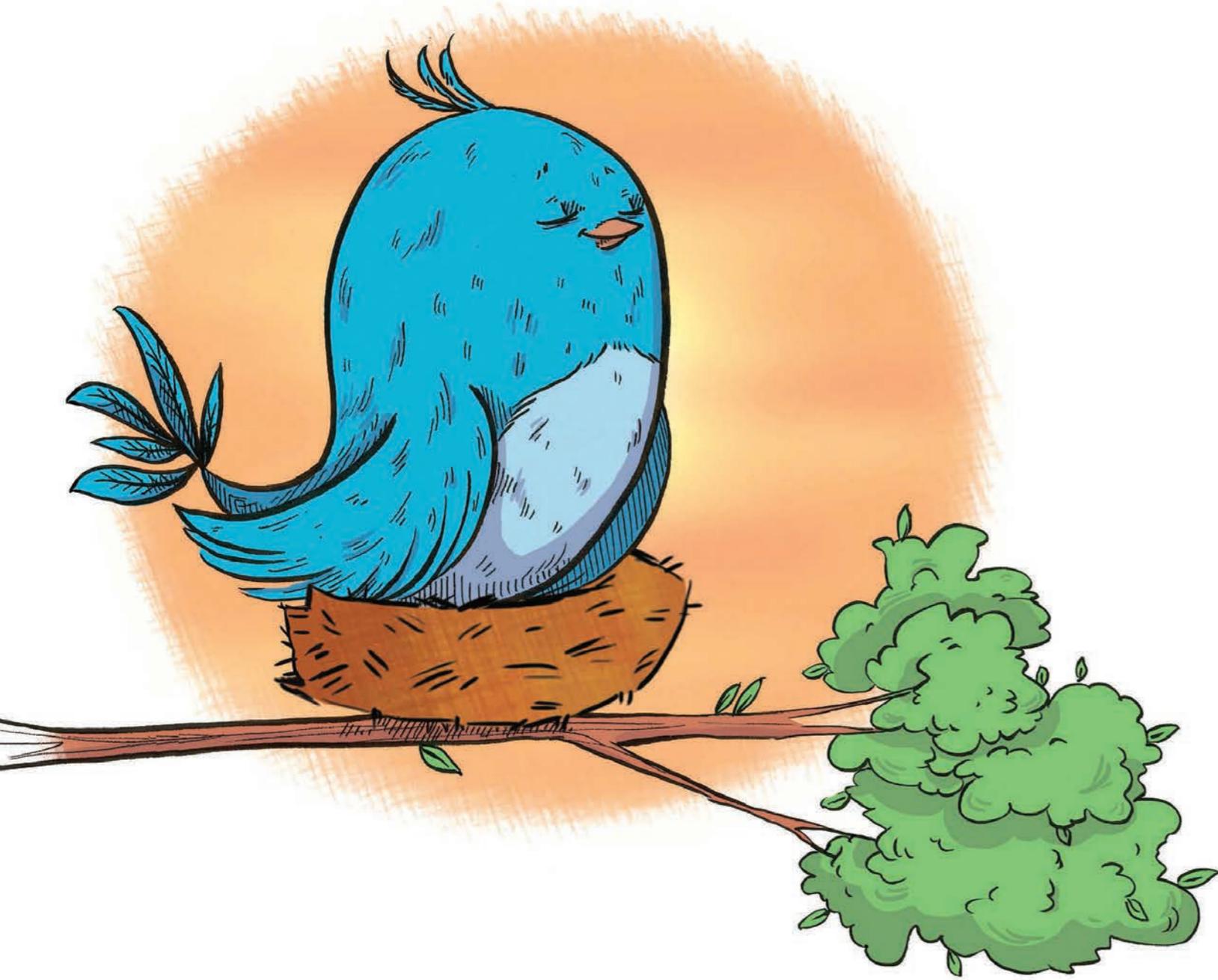
One hot summer evening, as the orange sun was taking a while to set, Arno's disease knocked on the door and took away his ability to hear.

Arno's parents cried at the thought that their beloved son would soon no longer be able to hear the sweet melodies his mother sings to him.

The parents, outraged, cried out in despair:

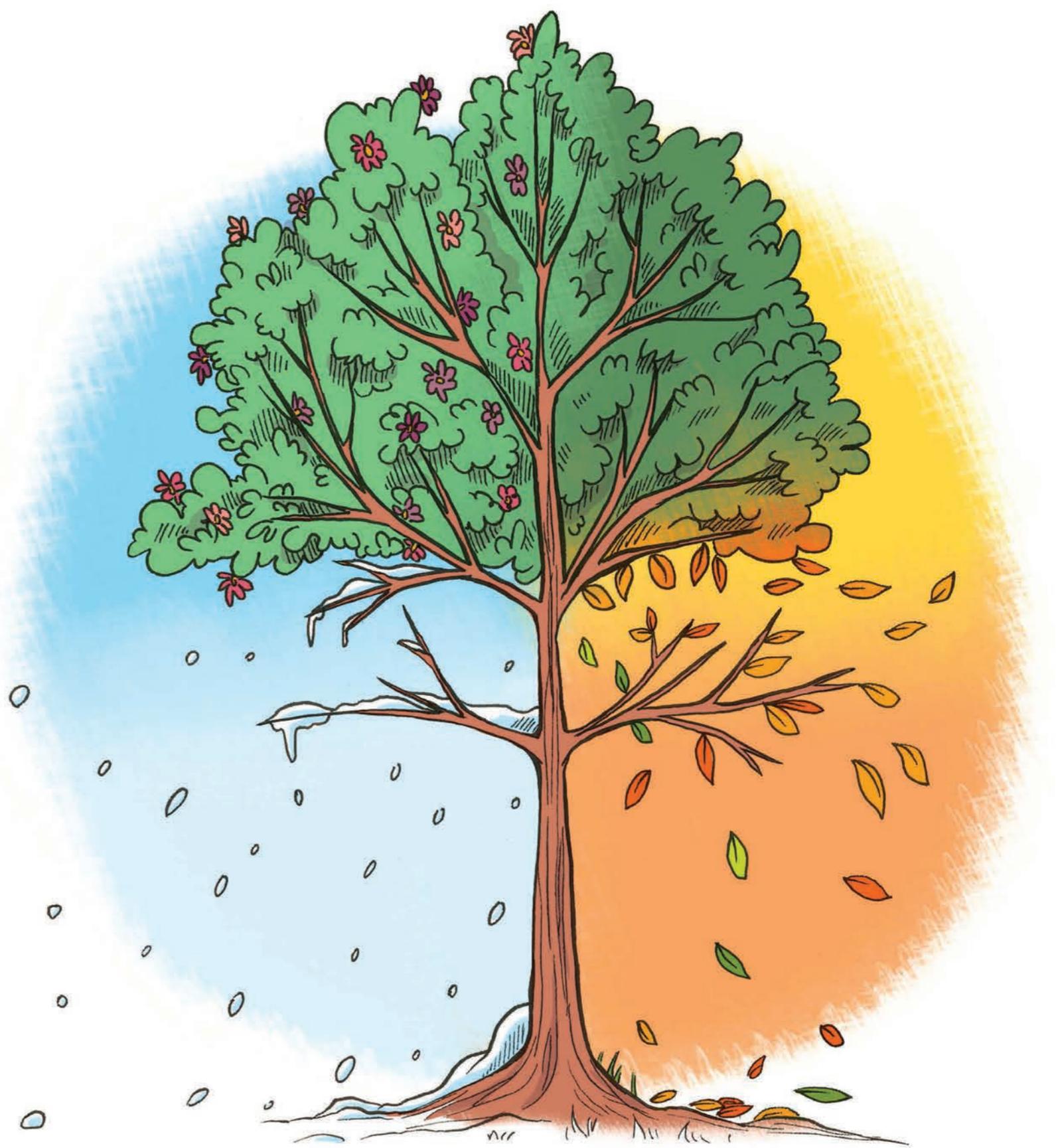
“But what is there left for our child now?!”

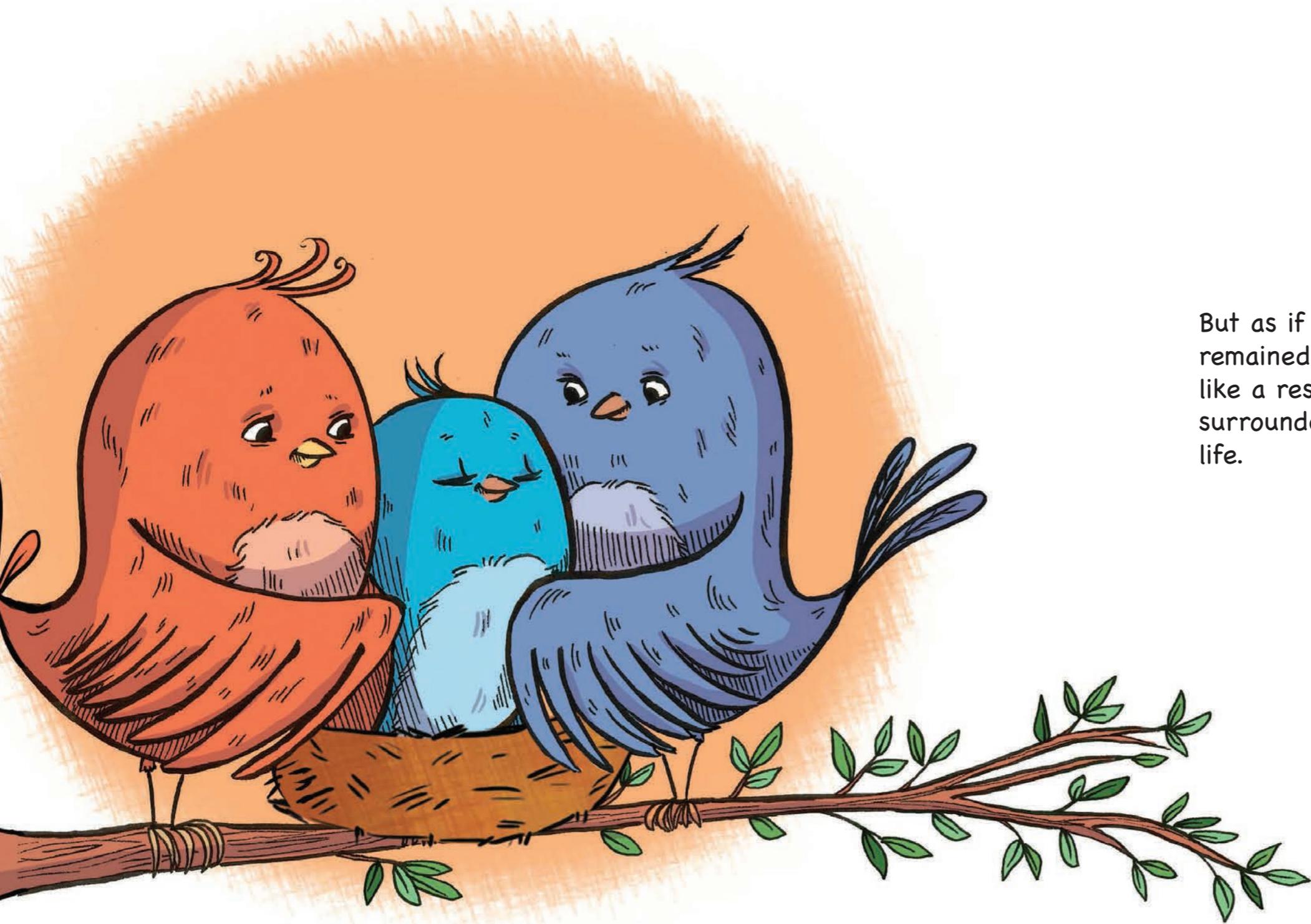




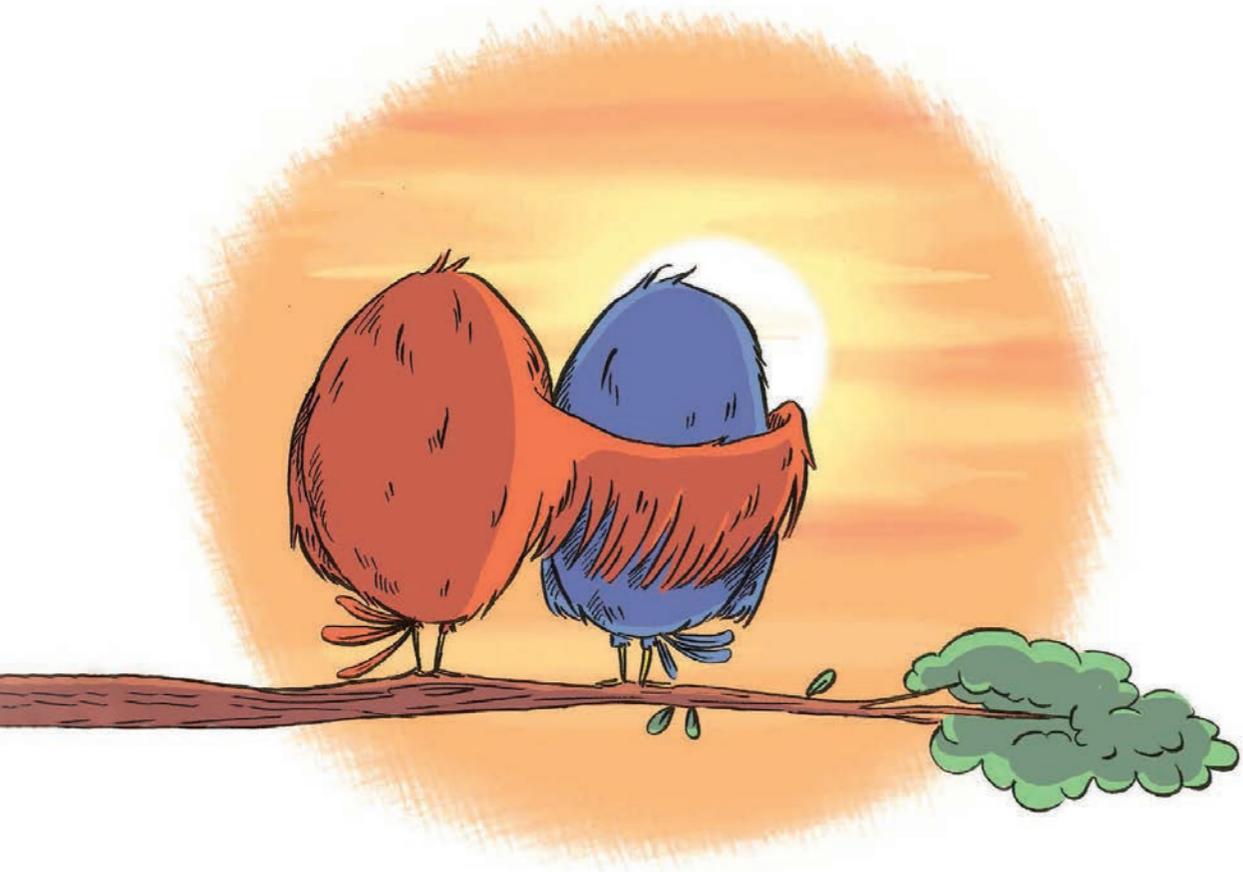
"Look, the wind whistled at them, his smile remains. He still has his smile to show you how much he loves you..."

Time passed and seasons went by.





But as if eternal, Arno's sweet smile remained on his face. His smile was like a response to the love that surrounded him, like a response to life.

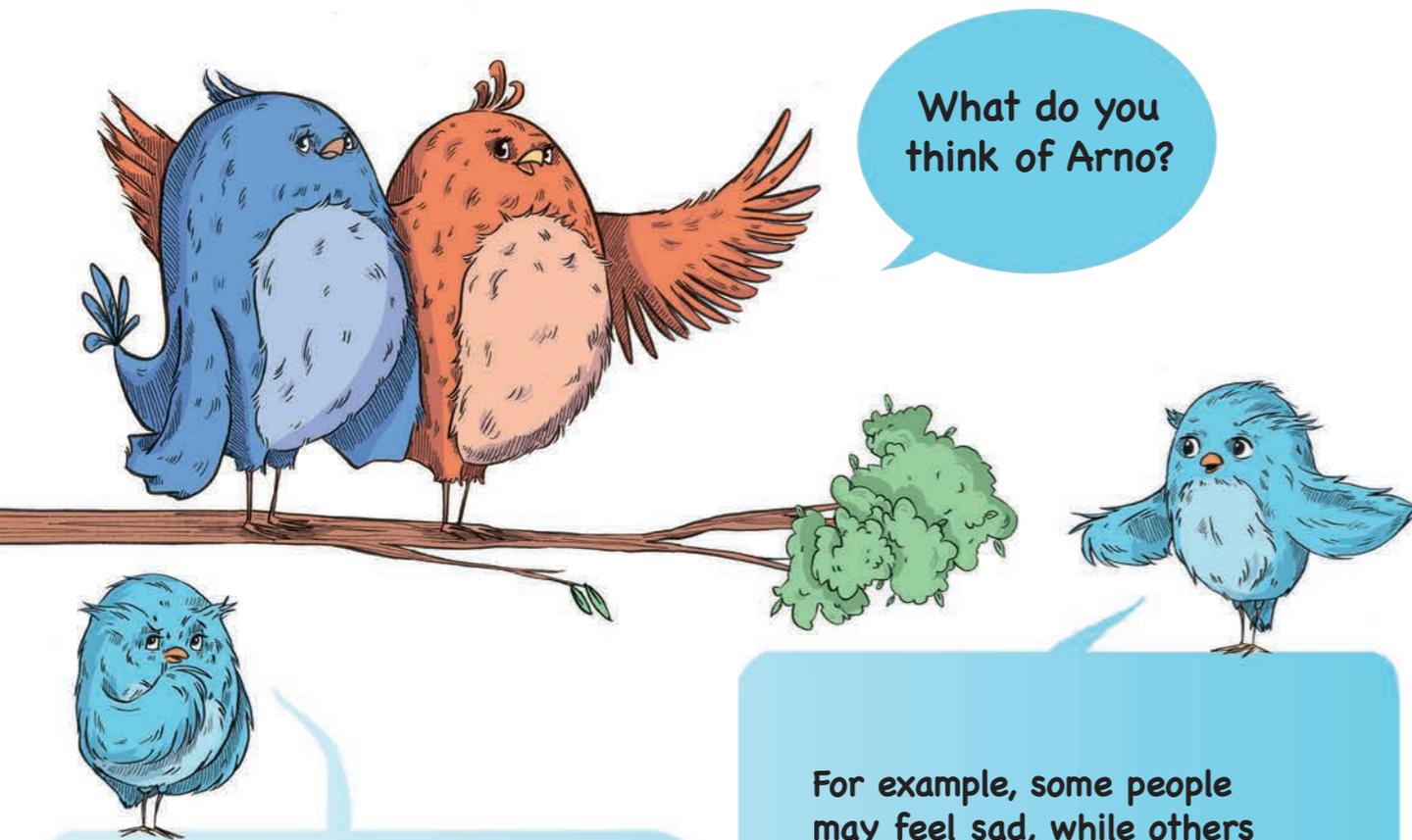


Arno's smile is something that his disease will never take away.

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 Arno?

Do you know anyone who has, or has had, a disease similar to Arno's?

In your opinion, how do you think Arno's parents feel? Anger, sadness, injustice, loneliness?

How do you feel when someone you love dies?

Did you know that each person could feel different things when someone dies?

For example, some people may feel sad, while others may feel angry. They can also express it in very different ways. By crying, laughing nervously, shouting, or even not showing anything...

Did you know that children, like adults, could be afraid of death and find it difficult to talk about it? What do you think about it?

If you feel the need to, don't hesitate to talk about it at any time. It will do you good.

About Metachromatic Leukodystrophy

The term leukodystrophy refers to a group of diseases, of genetic origin, which affect the myelin in the brain, a kind of insulating and protective sheath surrounding the nerves and neurons and ensuring their proper electrical conduction. Leukodystrophies are degenerative diseases. Currently, there are several dozen forms of leukodystrophies. Depending on the type of leukodystrophy, the symptoms may vary. In general, neurological manifestations can occur at any age and are progressive – balance disorders, tremors, motor disorders, intellectual disorders (memory, comprehension, behaviour), and sensory disorders (vision, hearing). There is usually no treatment for these diseases, and they often lead to premature death. For some leukodystrophies, research is progressing to try to identify specific treatments to slow down the disease process. In the case of metachromatic leukodystrophy, there are 3 subtypes: the late infantile form (60%), the juvenile form (20 to 30%) and the adult form (10 to 20%). The late infantile form begins at walking age, with the progressive appearance of eating and swallowing disorders, seizures, and progressive loss of walking, speech, vision, and hearing, leading to premature death.

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/>



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 100 countries, for people of all ages and cultures. Fondation Ipsen BookLab publications are provided free of charge to schools, libraries and associations.

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Arno is an adorable little sparrow full of energy.
But one day, the wind told his parents that Arno
had a disease that would take away the beautiful
things he had acquired over the years.

However, despite life's injustice, Arno's smile
remains. His smile is an eternal memory of a
premature flight.



“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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Have your say!



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