

The indigo stork

The dream of a little girl who lives with a rare disease



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Illustrations: Adolfo Ruiz Mendes



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**Dedicated to all those
families with special,
different and unique boys
and girls.**

What is normal? What things do we call rare? What is the difference between unique and special? These questions are raised for us in “The Indigo Stork”, a story about the value of difference and the importance of putting oneself in someone else’s place. This tale of Vehia and her sister Naila, who has a rare disease, shows us the importance of valuing and caring for the “indigo storks” that exist in each and every one of us.

At Pfizer, we are committed to health education. As such, we are offering this story out of the belief that it is one of the best teaching tools for explaining to little ones - and to larger ones too - values like respect, equality and empathy, which are key to living in society.

We hope that this story will give children, parents and relatives time for reflection, enjoyment and learning. Above all, we trust that we can keep disseminating our philosophy and *raison d’être* in a manner that is different but that has the same purpose in mind: to achieve, all of us together, a world that is increasingly healthier and more committed to health.

Sergio Rodríguez

Country Manager Pfizer Spain



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Hi, my name is Vehia and I'm going to tell you about my family.

Like every other Monday, my Mum has left the house early to take my little sister to see the doctor again. Then my sister has to go to her exercises; she does a sort of gym that helps her to get stronger and to straighten up and walk better.





Later on, she has to do movements with her mouth and her tongue, with a different doctor, I think. This is because we don't understand her when she talks...

although she doesn't speak much, she's really funny.

On other days, she goes swimming and also to a special school where Mum talks to some other people while Naila is playing. That's why my older brother Danel, who is 15, is often the one who takes me to school.



So why is my sister's life so special?

One day, when Naila was little –she's two and now she's big like me, because I'm six- Mum and Dad explained to my brother Danel and I that Naila has something different. And that's why it's hard for her to climb stairs, eat on her own, speak like other children of her age and some other things.

It seems that she's got a rare disease. And no pills, creams or injections can cure her of what she's got. Nobody knows very much about her disease but at least it doesn't hurt her at all.

Mum and Dad said that they're going to do whatever they can to get a doctor to talk to more clever, expert people and find a pill or a medicine so that Naila isn't so different.





The last time I saw the doctor I was given some glasses to wear because I couldn't see the drawings or the letters on the blackboard. I love them; they're pink and lovely. We all chose them and I look really pretty in them.

I then asked why I have to wear glasses and my brother and sister don't. Dad said that

everyone is different and that's what makes someone special.

My brother Danel is also different; he has to wear a brace to make his teeth go straight. Everybody has different things happen to them. I think they teased Danel at school at first. They're really silly. Don't they know that there's nothing wrong with it?

I think I'm understanding this better.

Everybody gets something: I get glasses; my brother gets a brace on his teeth; and Naila gets something rare.



Those days, Mum and Dad seemed more worried and upset; they talked on the phone a lot and they went to meetings etc.

Dad had to leave his job because he said his new job was Naila now.

And us too, of course!

Mum agreed because she's a nurse and her shifts make it easier for her to be with us.

I don't understand very much about this.

I love playing with Naila and Danel, who drives us crazy and hides to give us a fright. That's when he's not got his homework to do, of course.



When I got to school, I told my classmates how special my sister was. Since then, they have been really nice to me and say lovely things about her. Everyone except Fernando, that is.

Fernando isn't a nice person and he makes fun of her: "Your sister's a duck!" I really don't like it when he says that so I just ignore him.



When I asked Mum why Naila was different

and why she couldn't go to school with me, she told me this:

–You see, darling, the new babies who come to families are brought by a stork.





**Ah, I get it! I know
what storks are like!**

Dad showed me them in the animals' book, that one that we like to look at all the time. And we saw them when we went on that long trip to that town, didn't we, Mum? We saw where they lived: in a really big nest, on top of a church. I remember them really well.

—Yes, you're right, Vehia. They were black and white, with long legs and large beaks.

-Well, the stork that brought Naila was an indigo stork;

one that was really different from the rest; it was really special, really lovely and really unique among all of them. And it left a little person who was different too: special, beautiful and unique.

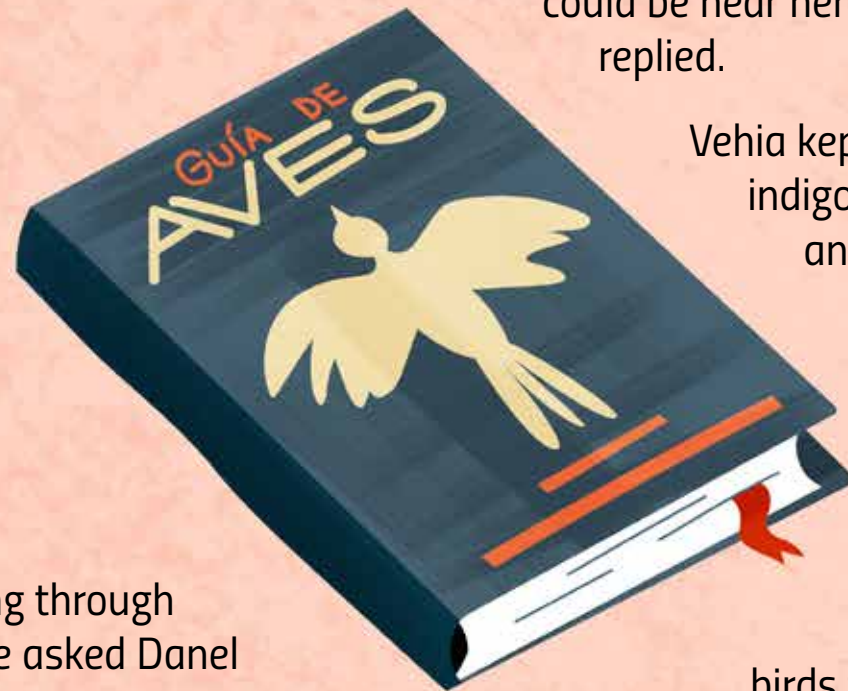
-I want to be a vet and study storks with that colour! -I told Mum.



After these explanations, Vehia felt a desire to see that indigo stork one day.

She wanted to ask it questions. She wanted to know why it was so different and so rare, just like Naila.

She wasted no time in browsing through the animals' book and then she asked Danel where storks could be found.



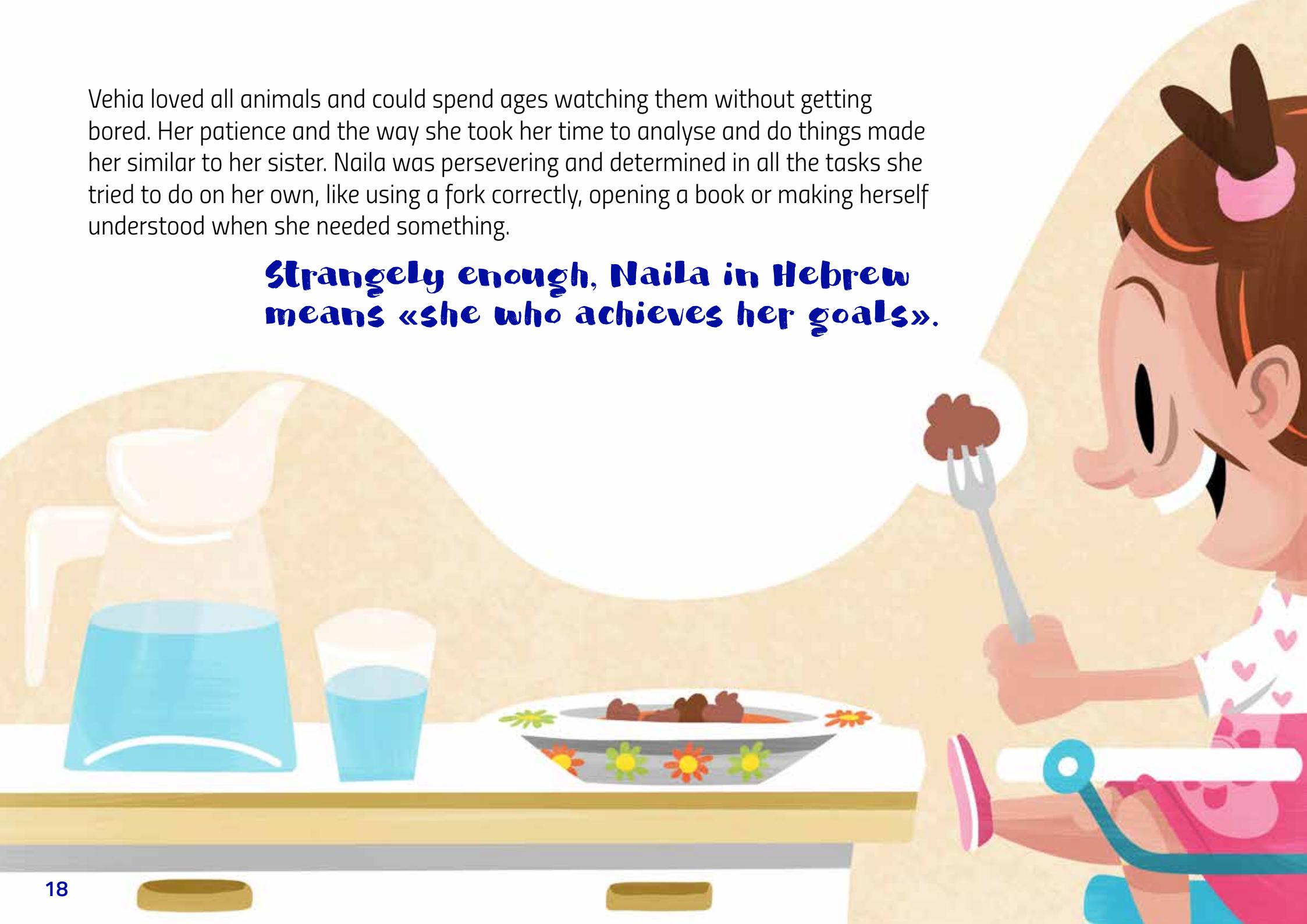
–You have to wait until the good weather comes; storks go to another continent to spend the cold winter there, so any day now they could be near here flying by– her brother replied.

Vehia kept wanting to see the indigo stork. She spent hours and hours looking through her bedroom window, from where she would be able to catch sight of it if it passed by, because in the area there were often a lot of other birds flying about.



Vehia loved all animals and could spend ages watching them without getting bored. Her patience and the way she took her time to analyse and do things made her similar to her sister. Naila was persevering and determined in all the tasks she tried to do on her own, like using a fork correctly, opening a book or making herself understood when she needed something.

Strangely enough, Naila in Hebrew means «she who achieves her goals».





How odd! -Vehia often exclaimed. -The indigo stork never appears in any of the stork photos.

And she went back to her place by the window as if it was a look-out post.

At school, she was a very bright girl and her results were really good. She was loved both by the teachers and the pupils, who would always ask about Naila. Although, of course, the exception who proved the rule was always Fernando. On some days, he was even punished for his bad behaviour in class.

Vehia dashed out of her bedroom to find Danel, who was doing his homework



in his room: "Danel! Danel! I've seen it! It flew by my window! It stopped and looked at me".

It was beautiful! It had a colour that was so different and amazing that I couldn't stop looking at it; it was special and unique, just like Mum told me...

**unique and special
Like Naila!**



Her brother stopped her in her tracks.

–Have you seen it???

–What?

–The indigo stork!

As delicately as he could, while giving her a kiss on the cheek, Danel replied:

–Vehia, I wish I could have had a nap as good as yours! You were lying on your cushion and the warm sunshine coming through the window made you drop off.

And the indigo stork came to visit you in a lovely dream.

–That’s not true! It was real! The stork told me that it was passing by because it had to leave another special baby at somebody else’s house.



–And it also told me that,
**even though it
was unique,
it would like
to be the
colour of
the other
storks
because
it felt as
if it was
always
being
stared
at and
it felt
lonely.**



I have to find out who painted it that colour, when it went indigo and whether it could be the same colour as the other storks or whether there are more storks with that colour and where they are. Why do they come when you don't ask them to?



I'm going to do the same as Mum and Dad do with Naila: I'm going to look for clues and paths and show all my friends that they exist and that, even though they've never seen them, they are in some place and they could go to your house at any time with a unique, different baby like them and like Naila.

At that moment, her father came in. He'd been making the dinner in the kitchen.

–Dad, I'd like to do some discovering. Will I be able to do it? What will I need?

Her father was about to answer when Mum and Naila opened the door and entered the house. It had been another tough day, one that was full of exercises, care and therapeutic games.

Vehia forgot about the questions she'd asked her father and went running towards them:

–Hey! I've got loads to tell you about!





Suddenly, she realised that they had not come home on their own. Fernando, her horrible classmate from school, was with them.

Vehia was really cross: why did he have to come to her house with her sister and her mother?

But before he could reply, her mother said:

–Vehia, Fernando would like to talk to you.

– Erm... Vehia, I... want to say sorry for being so nasty all the time..., I... –and he burst into tears.

Vehia's mother finished off his sentence:

Fernando has had a little brother who has the same disease as your sister and...



**The indigo stork
was going to
your house!**

—said Vehia without letting her mother finish. She gave Fernando a hug—. Don't worry. I'll help you all I can. I know a lot.

The boy was surprised by how kind Vehia was. He smiled.

—Mum, we have to
find more indigo
storks!



Her mother started thinking. Without realising it, Vehia had had a great idea: to find more families with special children! She looked at her daughter proudly.

Meanwhile, Vehia said to her sister:

–Come here, Naila, do you like the colour indigo? I've met a stork that was that special colour; it's a rare stork but it's unique, like you.

**Do you want
to be indigo?**





-The End-



The news that we have to confront a disease always catches us unprepared. And much more so if this is a rare disease, where the path to diagnosis is usually lengthy and full of uncertainty. If it is one of our children who suffers the disease, all the feelings, doubts and emotions multiply and flood in so that it is very difficult to manage the family's day-to-day affairs.

The lack of knowledge that surrounds rare diseases does not only apply to those who suffer them and their environment; this shortfall is also common among doctors and society. Therefore, it is very difficult to find tools that help us to withstand or resolve both the small doubts and the larger issues that arise daily. This is where the sky clouds over and despondency assails families, when a feeling of solitude takes hold of us and we question the reason for everything.

This is when those who have suffered just like us, or those who are suffering at this very time and accompany us on the journey, appear as if by magic; this is when patients' associations provide support to families that need help. These associations work to group people with very similar experiences and situations where everything is shared, where those people provide each other with help in a show of absolute generosity, where the information that we feared we would never find becomes available and where we encounter resources that we need but that nobody has given us.

"The indigo stork" intends to keep clacking away to draw attention to the importance of how to approach things naturally and non-judgmentally; it is not important what happens to us, what is important is how we face up to it.

Mario Torbado

Pfizer Head of Relations with Patients' Associations

Other books published

- Mi primer viaje al Sistema Solar (My first voyage to the Solar System)
- Viaje a las estrellas (Voyage to the stars)
- La guerra de Troya (The Trojan War)
- El descubrimiento de América (The Discovery of America)
- Amundsen, el explorador polar (Amundsen, the polar explorer)
- Atlas infantil de Europa (A child's atlas of Europe)
- Las malas pulgas (Bad temper)
- El reto (The challenge)
- Descubriendo a Mozart (Discovering Mozart)
- Sácame los colores! (Show me your colours!)
- La Historia y sus historias (History and its stories)
- Descubriendo a Dalí (Discovering Dalí)
- Cocina a conciencia (Cooking with conscience)
- Descubriendo a Van Gogh (Discovering Van Gogh)
- Apolo 11, objetivo la Luna (Apollo 11, Objective, the Moon)
- El Lazarillo de Tormes (The Life of Lazarillo de Tormes and of his Fortunes and Adversities)
- Descubriendo a Mondrian (Discovering Mondrian)
- Mi primer libro de historia (My first history book)
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