

CHILDREN OF GENETICS

Sonia Goerger and Élodie Garcia

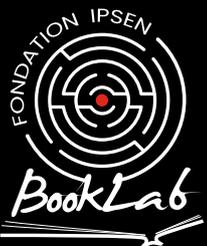


Wolky, the Little Wolf



European
Reference
Network
for rare or low prevalence
complex diseases

Network
Intellectual Disability
and Congenital
Malformations (ERN ITHACA)



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Once upon a time, in the middle of a clearing, in a pretty wooden cottage, there lived Grandmother Wolf and Grandfather Wolf.

Every Wednesday, their nine grandchildren would come over for a get-together that none of them would have missed for anything in the world! Grandfather Wolf was so funny. He was never the last to get into mischief! As for Grandmother Wolf, she would pacify the young wolves with her sweetness and calmness.

At snack time, they would all gather around the fireplace with a cup of hot chocolate to listen to Grandmother Wolf's story.

"Tell us a scary story!" an impatient young wolf said.

"No, an adventure story!" another asked.





After a few seconds of reflection, Grandmother Wolf said:

“You are all grown up now! I’m going to tell you a true story. This is a story that happened when I was a child: the story of my most beautiful and extraordinary meeting!”

"When I was a child, I was very shy. It was quite difficult for me to talk to other people and make friends. This caused me a lot of difficulties in my daily life.





One day, Mrs Owl, our teacher, introduced us to a new pupil. His name was Wolfy. He was a tall, skinny young wolf with a slightly hunched back and beautiful blue eyes. He had a birthmark, a heart-shaped, garnet-coloured spot just below his muzzle, not far from his mouth.

This birthmark was not his only characteristic. Wolfy was slower than other wolves of his age. He had difficulty speaking properly and understanding certain things. Mr Fox, a retired teacher, would stay with him in class several times a week to help him understand his lessons and do his exercises. The other days, most pupils would say he was a complete idiot, and he had no friends either. I was way too shy to go and talk to him.





A few weeks after his arrival, Mrs Owl asked us to learn a poem. Then, we had to recite it standing up in front of the whole class. That was a real challenge!

When it was my turn, no words could come out of my mouth. I stood frozen in front of my classmates. They were stunned and kept staring at me. I was like paralysed and my legs were shaking. Mrs Owl, who probably thought that I simply did not know my poem, was running out of patience. When all of a sudden...

... BOOM! A huge noise from the back of the classroom was heard! It was Wolfy who had fallen off his chair, taking with him all the books, notebooks, and pencils, which were on his desk!

All the pupils in the class began to laugh and clap. What a racket! Mrs Owl was too busy calming everyone down, so she asked me to go back to my seat.





As I went back to my seat, relieved and happy to have made it, Wolfy's eyes met mine. He smiled and winked at me. I then realised that his fall was not accidental at all. Wolfy had fallen off his chair on purpose so that he could help me! He had understood, unlike everyone else, what I was feeling.

He had seen what the others had not.

From that day on, Wolfy and I became inseparable. I got to know him and discovered that he was a funny and exceptionally kind wolf. He even helped me become less shy."

"You see, kids," concluded Grandmother Wolf, "there are many kinds of intelligence. But, in my opinion, the intelligence of the heart is by far the most remarkable".





Once Grandmother Wolf finished her story, the room stayed silent for a few moments. Only the crackling of the fire could be heard. The children exchanged knowing glances, touched by the lovely story they had just heard. A wolf pup smiled knowingly at Grandmother Wolf and stood up. Then two, then three... soon followed by the rest of the pack. Grandmother Wolf got up as well and went to the sofa, on which Grandfather Wolf had fallen asleep.

She covered him with a blanket so that he would not get cold, then tenderly kissed him just below his muzzle, not far from his mouth...on a heart-shaped, garnet-coloured spot.

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 Wolfy?

I find him different.

If a child answers:

I didn't notice anything special about him.

You can ask:

What does "being different" mean to you?

And you, do you feel different?

Do you know anyone who is different from your surrounding?

How do you think it feels to be different?

How do you react to someone who is different? Do you want to help them?

Have you ever made fun of someone?

Wolfy needs someone to be with him in class to help him. What do you think about that?

Have you noticed that Wolfy has a little spot on his face, above his mouth?

What do you think about the fact that Wolfy has no friends and is made fun of?

About Intellectual Development Disorder

Intellectual Development Disorder (IDD) is a neurodevelopmental disorder that begins during the developmental period (before the age of 18). It is characterised by significant impairment in intellectual functioning and autonomy, impacting many areas of the person's everyday life. IDD is one of the major neurodevelopmental disorders and affects 2% of the population or more than a million people in France. Unfortunately, in about 50% of cases, the cause cannot be determined. The treatment of an IDD depends on its seriousness. Most often, it is multidisciplinary and involves many people: psychologists, psycho-motor therapists, speech therapists, etc. More rarely, there are specific treatments. It is important that disorders are detected early: we now know that the more the child is stimulated, the better his chances of becoming independent in the future. Schooling can therefore be adapted into specialised sections, aiming to deepen and help children acquire new abilities.

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

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At snack time, by the fireplace,
Grandmother Wolf tells her wolf pups the
story of Wolfy, a strange little wolf
who had difficulty speaking and
understanding certain things.

A little wolf with a heart-shaped,
garnet-coloured spot near his mouth...



“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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