

CHILDREN OF GENETICS

Sonia Goerger and Élodie Garcia



# Charlotte, the Little Marmot



European  
Reference  
Network  
for rare or low prevalence  
complex diseases

Network  
Intellectual Disability  
and Congenital  
Malformations (ERN ITHACA)



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# Charlotte, the Little Marmot

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The story begins in the heart of the Pyrenees Mountain range, at an altitude of 2,000 meters. In the middle of the night, everything is calm in the marmot's burrow. While everyone is sleeping, a soft melody resonates in the air. Mummy Marmot is singing a lullaby to her daughter Charlotte because, as it has been every night for years, Charlotte the little marmot refuses to fall asleep.

The next morning, Mummy Margot struggles to wake up because she barely managed to sleep a few hours. As for Charlotte, she is full of energy! Restless, she shouts and runs all over the burrow. Charlotte hardly speaks at all. Very often, shouting is her only way to communicate.





The other inhabitants are annoyed by Charlotte's behavior and their patience is running thin.

So when Charlotte ends up breaking a vase, they have had enough!

"Take your daughter outside! She is out of control here! It is unbearable!" one of them tells Mummy Marmot who, embarrassed, immediately complies.

Mummy Marmot decides to take Charlotte to the lovely flowery meadow nearby. There, there are many families who want to enjoy the last sunny days of the summer. The parents are talking to each other while watching their children playing. Mummy Marmot, worried, warns Charlotte.

“You can go play, but behave!  
If there is any problem, we will  
leave at once!”

Charlotte nods and hurries to join  
the other kids to pick up flowers.





After fifteen minutes or so, some people begin to shout and cry. A circle has formed around the kids. With difficulty, Mummy Marmot clears a path to see what is going on. What she feared so much is confirmed. She sees Charlotte on the ground, hitting one of her playmates.

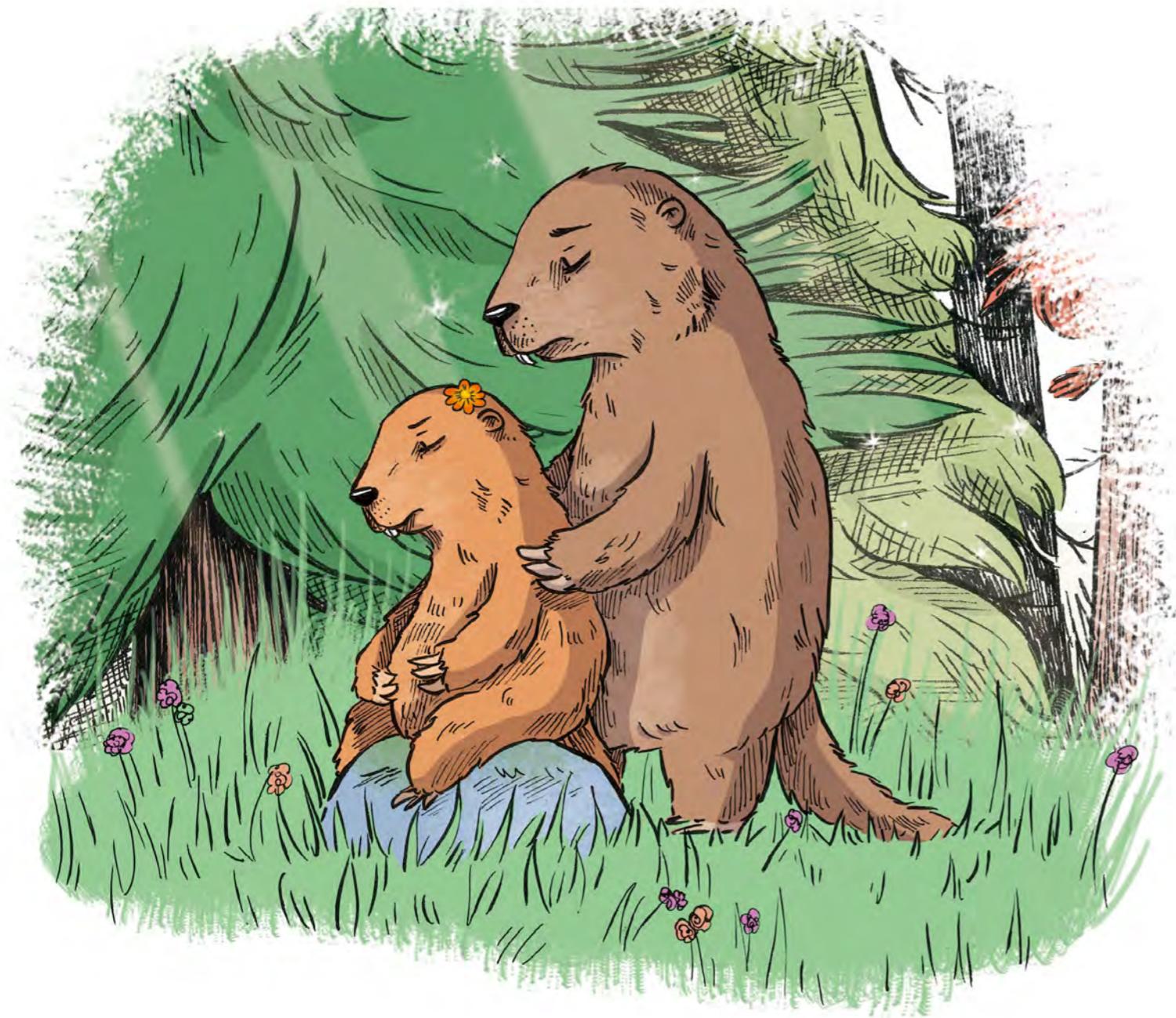
Mummy Marmot rushes to separate the two children. The little marmot takes refuge in his father's arms, crying. The other parents are glaring at Mummy Marmot. She catches some snatches of their conversation.

"What a rude child!

- This little marmot is different, she only expresses herself through violence. She shouldn't be allowed to play with other children."

Hearing these hurtful comments, Mummy Marmot takes Charlotte by the hand and leaves the place.





A little further away, in an isolated place, Mummy Marmot and Charlotte stop for a moment.

Charlotte is still troubled by what just happened. Sat on a stone, huddled in on herself, she rocks back and forth to try to reassure herself.

Mummy Marmot cannot help but cry and lament. What should she do to improve their daily life? How could she help her daughter?

Suddenly, as if someone has heard her thoughts, a young fox comes up behind her and speaks to her with a kind and comforting voice.

“It is not your fault, nor is it your daughter’s. You simply need help. You can’t do it alone.

- Who are you? Mummy Marmot asks, distrustful.

- I am Doctor Fox. My job is not to treat the body, it is to treat the mind!” he enthusiastically explains.





Mummy Marmot and Doctor Fox have a long chat together. Mummy Marmot readily confides in the young doctor and she explains him all the difficulties she has been facing since Charlotte was born. Because to be honest, although she loves her child, Mummy Marmot often feels overwhelmed by her daughter's behavior. Doctor Fox promises to help her. At last, someone listens to Mummy Marmot and understands her: she feels so relieved!

Since that day, Doctor Fox and Charlotte have been meeting. Doctor Fox's partner, Ms Weasel, is also there with them. She helps Charlotte make herself understood by others without getting angry or hitting them. After each meeting, Ms Weasel and Doctor Fox discuss the solutions they could propose to Charlotte and her mom. As time pass by, the three of them have managed to create a relationship of trust and a method of communication based on games.





"We can express ourselves in various ways, not just with words!" Ms Weasel likes to recall.

Doctor Fox has also prescribed Charlotte a preparation based on herbs and other secret ingredients. It helps her fell asleep and be calmer during the day. A new life begins for Mummy Marmot and Charlotte who now feel helped, supported, and at peace.

The night has fallen. Everything is calm in the marmot's burrow. While everyone is sleeping, a soft melody resonates in the air. Mummy Marmot is singing a lullaby to Charlotte...who soon falls asleep.

Mummy Marmot closes her eyes and smiles.

"Good night, my lovely little marmot..." she whispers before joining her daughter in sweet dreamland.



**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 about Charlotte?



### About her behavior

Do you know someone who sometimes gets very angry and can hit others?

How would you read in front of someone who gets really angry?

Do you know that children can have troubles controlling themselves when they are angry or when they cannot make themselves understood, like Charlotte who cannot speak?

Has it ever happened to you?

### About her sleep

Have you ever had troubles falling asleep, like Charlotte?

Do you sometimes have nightmares?

Have you ever felt angry or in a bad mood because you hadn't slept enough at night?

### About sleep and behavioral disorders

Sleep and behavior disorders are symptoms found in children with different types of rare genetic diseases. Behavioral problems correspond to a failed adaptation to everyday life. They manifest themselves as an action or reaction that does not correspond to the appropriate attitude and have an impact on family and social life. There are different types of aggression: auto and/or hetero aggression, disinhibition, opposition, provocation, stereotypes, eating disorders, etc. Sleep disorders manifest themselves in difficulty falling asleep, night terrors and nocturnal awakenings, nightmares, etc. They aggravate behavioral problems during the day. These problems are very difficult to manage for patients' families and friends, who often find themselves helpless and exhausted by this complicated daily life. Multidisciplinary care with a child psychiatrist and psychologist, focusing on sleep, communication, emotions... with a final focus on day-to-day behavior, is essential to help children and their families. It is also sometimes necessary, depending on the severity of the sleep and behavior problems, to introduce medication to help children regulate their sleep and stabilize the disorder. The GénoPsy Rare Diseases Reference Centre, which is part of the AnDDI-Rares health network, has a multidisciplinary team of experts to offer specialized care, and to improve the care and quality of life of people with psychiatric and/or behavioral disorders of genetic origin.

### 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" book series 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/>



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In the evening, when the burrow sleeps peacefully, Charlotte, the little marmot, is all excited. Mummy Marmot's soft lullaby cannot calm her and days are tough.

Will the Marmot family manage to channel Charlotte's boundless energy and get a goodnight's sleep?



“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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