

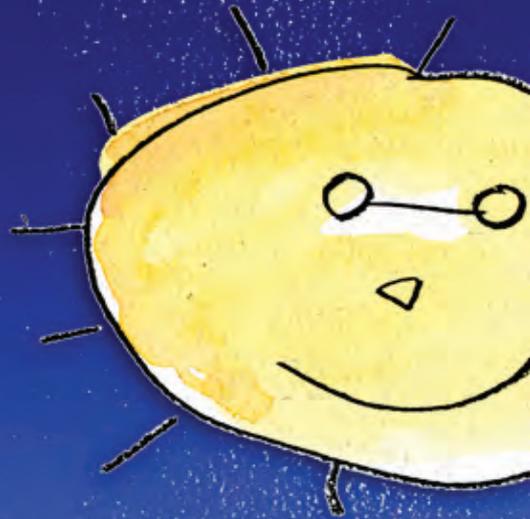
Marina Jurg

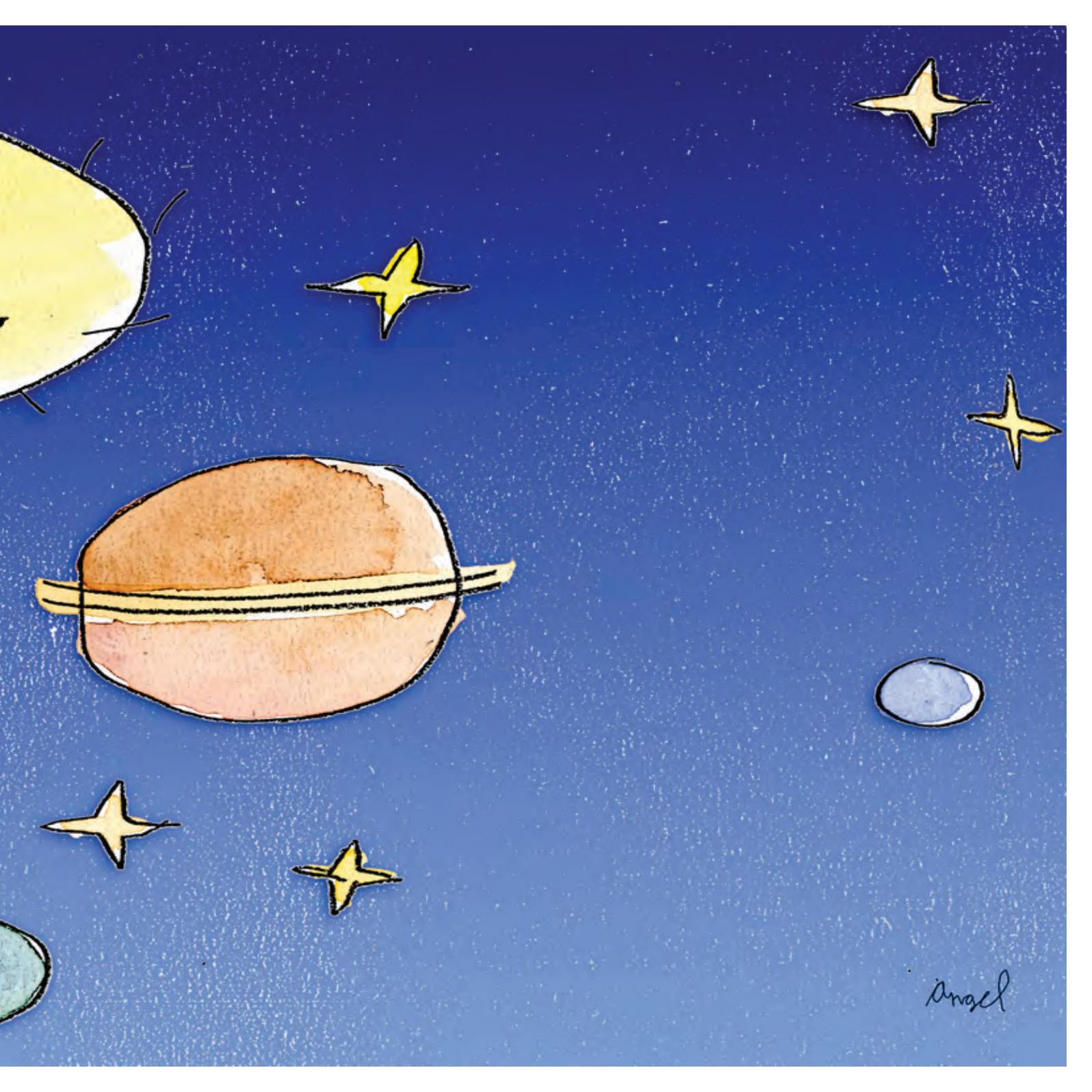
Maribel Pérez

# LUCIA

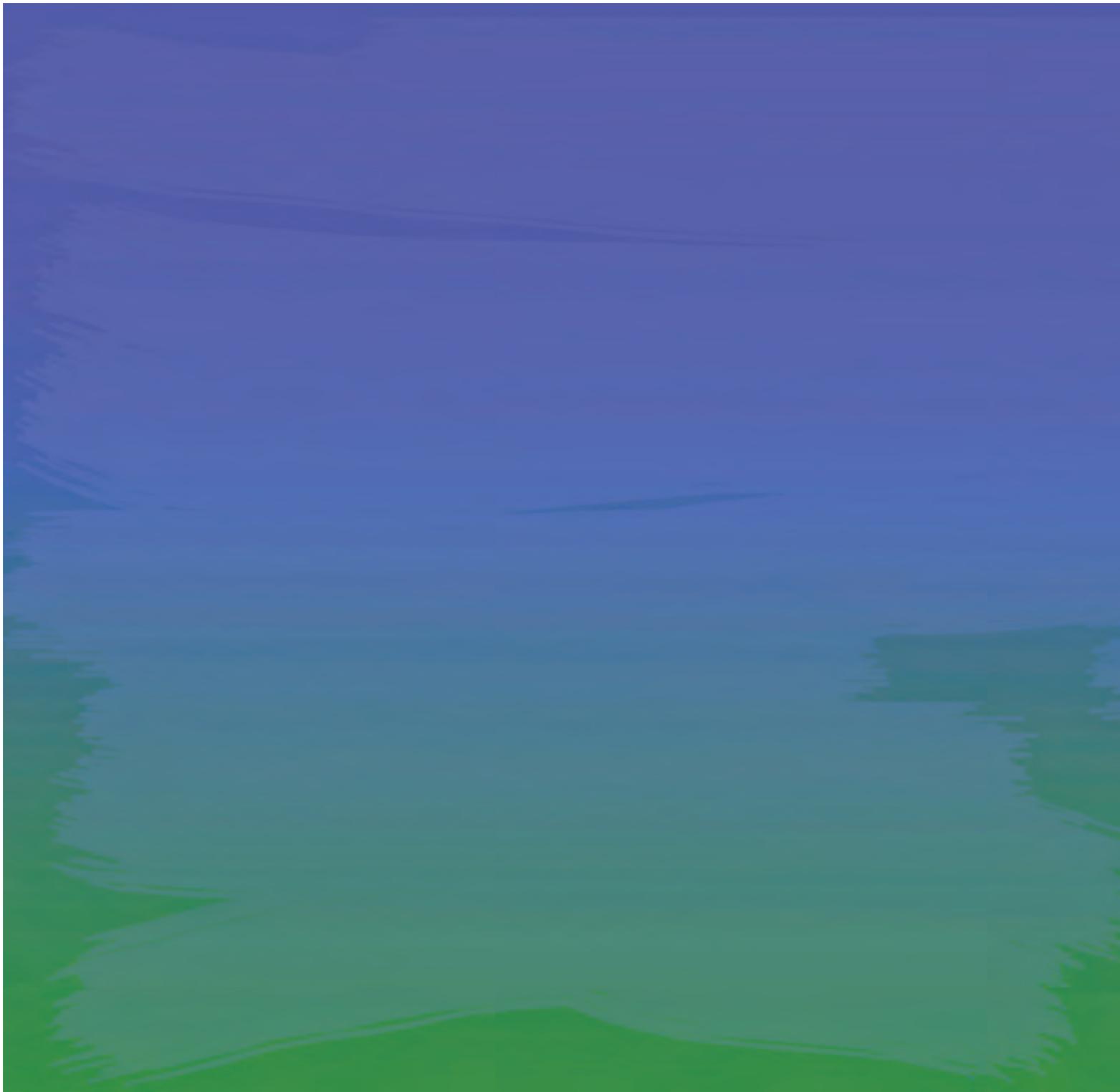


AND THE  
BLUE  
PLANET





Angel



Marina Jurg

LUCIA  
AND THE BLUE PLANET

with illustrations by Maribel Pérez

## Translator's Preface

The story of the book is...

...my name is Anne Agnew and I live in Catalunya, Spain. A Dutch friend and neighbour of mine, Marina, has written an exquisite little book called "Lucia and the Blue Planet", about the life and death of her daughter, Lucia.

Lucia was born with a metabolic disease, a peroxisomal disorder, and the prognosis was for a very short life. She lived for 10 years (1997-2007) on the family farm here in the Pyrenees. Physically she was profoundly disabled, with the mental ability of a one month old baby, BUT, from her family's point of view, Lucia operated on many different levels, and, by living with her, they realised that there was more to her life than was apparent on the surface.

Lucia's life story is written as a fairy-tale, telling the story of a princess born on a planet far out in space. Princess Lucia had heard of a beautiful blue planet, Earth, and wanted to visit us before all our pollution turns it grey. Despite being told by her father that differences between the planets would render her unable to see, hear, or even move, on Earth, she decided to come anyway.....

**Anne Agnew**



# introduction



**Lucia** lived for ten years, more time than we could ever have dreamed of. But, for me, it passed like a soft breeze of fresh air, because I longed to live with her forever. Her life was a mystery. While the memories were strong and fresh, I wanted to write about her. My friend Monique suggested a fairy-tale approach which fuelled my imagination. When the book was finished, Maribel, Lucia's teacher edited out almost a thousand words and embellished it with her beautiful illustrations.

My thanks to both of them and to all my family and friends, who had the good fortune to share the blue days with our little princess during her fragile life.

Marina (Lucia's mother)

**Once** upon a time there was a beautiful princess, who lived on another planet up in the sky and very far away from here. Her greatest dream was to travel here to visit the Blue Planet - Earth.

She had heard of its blue skies, fast running rivers, calm lakes and immense blue seas. In fact, this was a planet with so much water that it gave life to all kinds of trees, plants, animals and human beings. "So that's why they call it the Blue Planet," she thought.

But sadly, the princess also heard that things were not going well on the Blue Planet. The people who lived there had become totally dependent on machines to do everything for them. There were machines for washing, cooking, talking and even playing. This required factories, trucks, roads which resulted in a lot of pollution.

"Perhaps one day soon, they will call it the Grey Planet," she said sadly. But before that happened, she wanted to visit this beautiful world. She decided to ask permission from her father to make the long journey to the Blue Planet. The princess was young, healthy and very adventurous but her father, the King, knew that a trip to the Blue Planet would be very difficult and dangerous. "My darling, you can travel wherever you want, but not to the Blue Planet," he said seriously.

The princess looked so upset that the King decided to have a big meeting with four kings from neighbouring planets so that they could give their opinion. He organised a royal banquet and when it was finished, the princess waited to hear the decision of all five kings.





**The oldest** king stood up. There was a long silence. The princess twisted nervously in her chair. She swung her legs back and forth and tucked her long blonde hair behind her ears as she sat up straight to listen. The king cleared his throat and said solemnly, "In order to further our scientific knowledge, I think that the princess can make the journey to the Blue Planet..." There were shouts and cheers of encouragement but then the king added, "she can live there but she will not be able to move any part of her body, not even her head."

"WHY NOT?" cried the princess. "Because the air on the Blue Planet is very different from the air here on our planet," he replied.

**The second king** stood up to speak. "I agree that the princess can make this long journey, but unfortunately I must also tell her that on the Blue Planet, she will not be able to see with her eyes."

Teardrops dripped like wet pearls down the princess's cheeks. Not to be able to see the blue water, the pretty flowers, the green trees, the colours of the mountains, the white clouds..... Before she could dry her tears, the third king stood up to speak, "We have the technology to send the princess safely to the Blue Planet but we must also tell her that while she is there, her ears will not be able to hear any sound whatsoever." She now thought she had heard the worst. She could achieve her dream but without moving, seeing or hearing.....!

Surely the fourth king would continue with some good news but sadly he did not, "our scientists also believe that on Earth, the princess's brain will not develop normally. She will not be able to laugh, think or talk." There was a shocked silence. The king continued, "the gravity on earth is so strong that it will cause parts of her body to shake and sometimes her breathing will stop."





**The princess's** head was spinning! Her hopes were disappearing. It had been a dream, an impossible dream! How could she even think of making the journey under such difficult circumstances?

Finally her father stood up. He looked at her kindly and said, "only you can decide if you want to visit Earth. Although your stay there will be quite intense and difficult, I can also tell you that you will have some amazing experiences."

**“If you go,** you will enjoy many, many wonderful things. For example, you will enjoy the incredible sensation of touch and of being touched. You will smell the scent of a thousand flowers. You will take pleasure in the most amazing tastes and flavours. And most important of all, your human family will love you dearly.”

He continued, “You will feel their happiness and their sadness. You will teach them to be aware of what is important in life. Through you, they will appreciate the miracle of being able to breathe easily and deeply and enjoy eating healthy food. They will know the value of a relaxed body and sleeping profoundly well.”

**“You will** develop such an intense feeling for life that you will become immortal. Or as immortal as anyone can be on a planet where everything has a beginning and an end. One day, when you leave the Blue Planet to come back here and take my place on the throne, you will know the secret of all that is important in life.”

With eyes full of gratitude, the princess looked at her father and nodded her head in agreement. The following day, all the spaceships were ready to leave. A spaceship had also been prepared for the courageous princess, who had finally decided to go to the Blue Planet.



# **In the Montsec** mountains of Spain, a goatherd lived with his

goats. One day he was having a siesta under a great oak tree which gave lovely cool shade on hot summer days. His flock was tired as they had been walking and grazing since six o'clock that morning. Now the goats had full bellies and the sun was at its hottest, high in the sky.

Suddenly, there was a whoosh of wind and from nowhere, huge multi-coloured wings were circling above. The goats became very agitated and were jumping around in terror. The goatherd was awake immediately. He always slept with one eye open as he had to be alert to anything that might be a danger to his flock, such as wild dogs, eagles or snakes. He looked up and smiled. It was only a hanglider which had been flying too low and now was forced to land. The pilot gave an anxious wave to the goatherd. She was worried that he would be annoyed with her for scaring his animals. This had happened once before when she was flying in England. On this occasion the goatherd just gave a friendly wave as the goats seemed to have recovered and had already returned to their midday siesta.

The pilot quickly disassembled her hanglider and went over to apologise to the goatherd who was still sitting under the oak tree. She was so eager to meet a real goatherd, as in Holland, where she was born, they had all disappeared.

A few months later, the goatherd who was called José and the pilot whose name was Marina, met once again at the local village festival where they danced all night. They were so happy and decided to live together in the mountains where the air was clean and healthy.

**Spring** came, and one night José and Marina were laughing and talking together in the mountains. There were so many beautiful stars twinkling in the huge, dark sky. The couple became still and quiet. They felt so tiny and insignificant as they looked at the vast and unknowable black sky above them. The stars seemed to multiply and suddenly they saw one of them fall nearby. That night, Marina dreamt that she was going to have a baby.

In the months following this night, while the goats grazed peacefully in the mountain, Marina's baby grew bigger and bigger inside her tummy. Marina and José imagined how healthy, strong and agile their new baby would be, growing up in these beautiful mountains. They would always be together and their child's first playthings would be the baby goats, stones, tree branches..... Then with more brothers and sisters in the future, they would go for walks together in the mountains, search for lost goats and sometimes sleep under the stars.

Time passed quickly. The weather changed: strong winds were blowing and, for autumn, the sky was unbelievably blue. Marina was amazed at these skies just as she was amazed at how gently and curiously the baby moved in her tummy. Finally in January, the first winter snows came to the Montsec and so too, Marina's baby was born.



**Like** a falling comet, the princess arrived on earth and just before her head touched the ground, the midwife caught her. "What an amazingly easy birth!" she declared as she placed the baby in Marina's arms. "She is beautiful with such a brilliant light shining from her. We shall call her Lucía," said her parents as they looked into her eyes for the very first time.

The princess looked curiously at her new surroundings. "I can see!" she thought happily. "This is not what the kings told me would happen." The first thing she saw was

Marina's happy smile and the loving gaze of José. But behind them both, there was only a blinding white light. "This is supposed to be the Blue Planet! Where are the green trees, the brown mountains and the blue skies?" she thought anxiously.

A little later, as she was lying in bed with Marina, she heard a whisper in her ear, "don't worry, my little princess, soon we will bring you home". Lucía understood then that the blinding white colour and the strong smell of antiseptic were only temporary. "I can hear! The kings were wrong again!" she thought delightedly.

**Little by** little, a big celebration began around her bed. The whole family had come to see her. They thought she was beautiful. Lucía was delighted to see such happy faces and hear so many compliments. Everything was going well. There was only one problem, it was difficult to swallow so she could not drink any milk.





**Two days** later, José came to collect them both from the hospital. But unfortunately Lucía was not able to leave. She needed to stay in a small glass box which controlled her breathing, regulated her heart and gave her food. José and Marina could only kiss and cuddle their little girl for half an hour each day. When Lucía felt their hands caress her, she wanted to hold onto them and never let them go. But she couldn't. She had no strength, neither in her arms nor her legs.

Eventually the doctors discovered that Lucía was suffering from a very serious illness and they did not expect her to live for very long. They said she would be a fragile baby who would have problems breathing and suffer from convulsions. The worst news was that they could not do anything to help her. In the end, it seemed that the kings on her planet had been right.

Finally the day came when Marina said, "We will go home together and breathe the clear mountain air." Lucía could see her Mother's lips moving but she could only hear a buzzing noise in her ears, like the sound of a thousand bees singing. Strange things were happening to her body. José was so happy they were going home that he greeted her loudly and excitedly. Immediately her body began to shake uncontrollably. 

This was her first opportunity to experience the Blue Planet and her body was already out of control. Her parents stroked and kissed her, trying to relax her muscles in order to stop her body from shaking. As she lay on Marina's lap in the car, Lucía discovered something else. She could now only hear strong, deep voices, like that of her father. Then as she watched through the car window, the city faded little by little and eventually the mountains appeared.



**One** morning, José took Lucía on a trip to the mountain. He wrapped her up in a warm blanket and held her in a special sling around his neck. He liked looking at Lucía and took pleasure from her peaceful expression. He felt such love for his little princess. Lucía was really happy to be with her father, a patient man who was very observant and understood her very well. When she had hiccups or a stomach ache, he always knew how to help her feel better.

That day, It seemed to her father that the blue of the sky was shining out of her eyes and the two of them gazed happily at each other. Suddenly, everything went black for Lucía and she began gasping for air. Her eyes rolled in her head and her body began to shake. She felt his caresses, kisses and gentle words but later when she opened and closed her eyes over and over again, she could no longer see anything.

When they got back to the house, her cousins Jessica and Daniel were waiting to give her a bath. Jessica always cared for Lucía with such love. That day, she dried her gently, gave her a massage, put on her pyjamas and held her on her lap so that they could watch a movie together. "Aaaaaaaaahhhhhh," murmured Lucía. Although she could not see Jessica, nor hear the sounds of the movie, more than anything she could feel all of the emotions of this lovely moment.



**One** day when Lucía was practising her exercises on Marina's lap, she felt movement in her mother's tummy. She was so excited she wanted to run and tell everyone the wonderful news, but she couldn't. And then, just before her first birthday, her brother Ángel was born.

Almost every day, the three of them went to the mountain to be with her father while he looked after the goats. They rested together on the wild rosemary that smelled so good when it was in flower. Lucía could hear the strong cries of Ángel when he was hungry and she could feel him burping when he was full.

Time passed and Lucía observed the games of her little brother. She sensed when his sticks moved through the air as he hunted imaginary wild boars and she also felt the earth tremble when one of those huge animals fell to the ground. Lying on the mountain floor, she discovered how the wind played with smells. Her nose sniffed the aromas of pine, thyme, moss and rosemary. She noticed how the mountain air danced around her and she could feel the heat and light of the sun as it sparkled and shone through the leaves of the trees.

One evening after school, they were out walking and came to a place that was very beautiful and not far from the village. Like an oasis in this dry land it had a natural spring and a sparkling stream....all surrounded by the Montsec mountains. "Aaaaaahhhhhhhh," murmured Lucia.

She knew immediately that this was the perfect spot for her parents to build the house of her dreams. She had a vision of a house with a large living area and no stairs to contend with:—a house with easy access and a veranda big enough to hang hammocks. Ángel was totally in agreement and he shouted enthusiastically: "There is so much space here. Papa can house his goats safely and that means we can see him all the time."

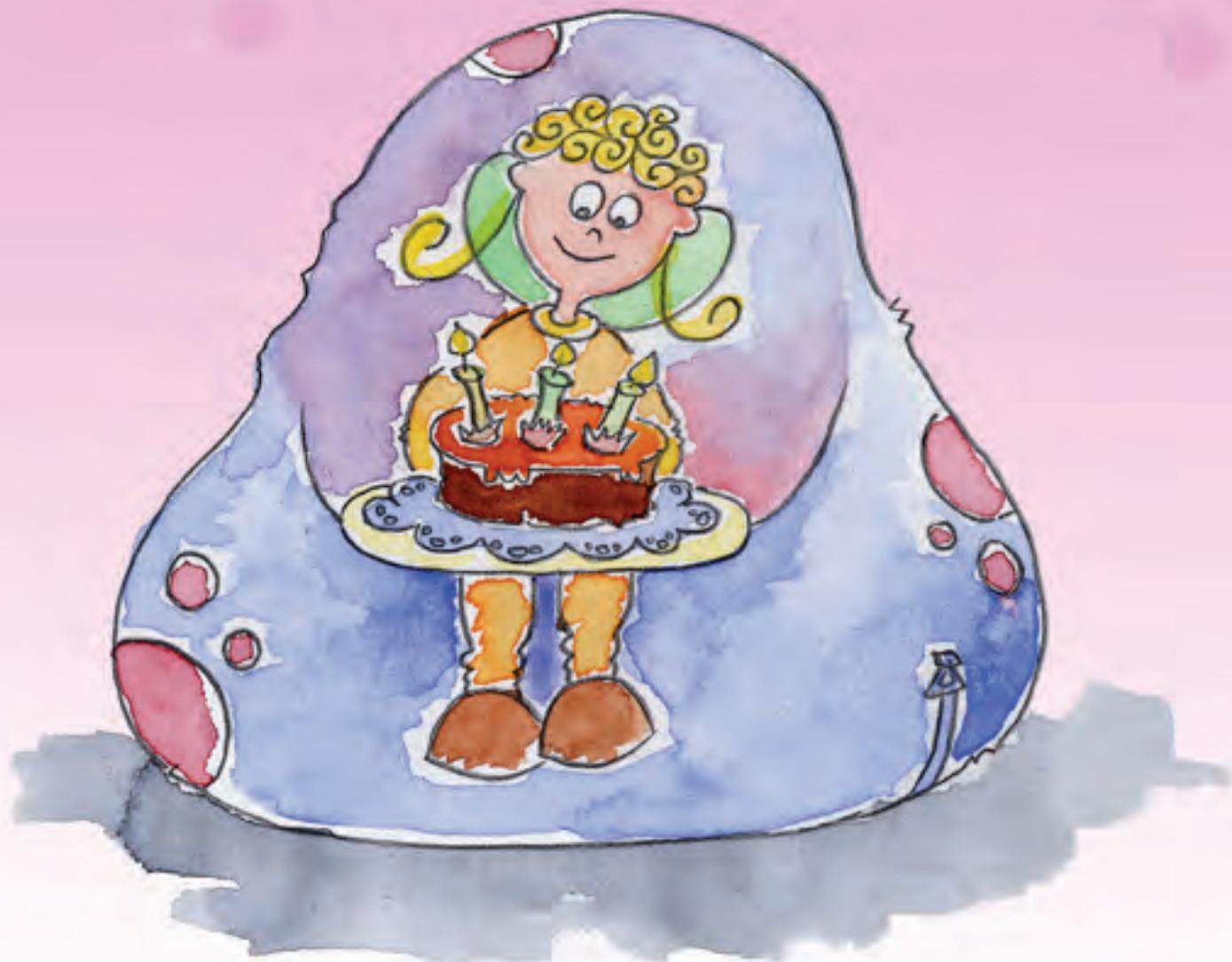
**So they bought** the land, built

a large shed for the goats and created a vegetable garden beside the spring. They also planted lots of vines and fruit trees. Finally they began work on their new home but before the house was finished and before they could move in, Lucía realised that once again her mother had new life growing in her tummy.

Marco grew up with the farm goats. Although they were the same age as him, he did not pay much attention to them. He preferred to rest side by side with Lucía. The two buggies were always together - by the vegetable patch, in the goat shed or at the new house.

When Marco began to crawl, he would bring Lucía all that he found on his little exploration trips, things like lollipops, pebbles, snails.....

One day, Ángel came to his parents and said that the children at school were asking about Lucia. They wanted to know what was the matter with her. Because of their questions, Ángel realised for the first time that his sister was different. He was surprised and happy to watch Marco grow and see that he was able to crawl, laugh and speak.





**The summer** months were the best. They went to the pool often. Here Lucía could float on the water with her head supported by an inflatable cushion. Sometimes she moved like a speedboat in the water. She loved the oranges and reds of autumn and the white of winter even though the low temperatures made her prone to colds. Better again was springtime - green and fresh with the songs of the cuckoos and nightingales. Their vibrating early morning concert was strangely comforting to her.



**In this** way, the seasons passed and with them the years that Lucía could spend with her family.





**At** their house, meals were always special. They were unhurried, full of fun and always included food grown on the farm. Everyone ate the same food - it's just that Lucía's portion was mashed up. She always ate in the same place - on her throne - Marina's lap.



**After dinner,** Lucía would invite her family on a voyage to the stars. As the light faded, she would take Marina's hand. Marina would then take José's and he would take the hands of Ángel and Marco. Faster than a rocket ride at a funfair, they would fly and spin through the sky. They flew so high that the Montsec seemed like a small dot near the Mediterranean and as they flew higher still, the Blue Planet looked like a small football. As light as feathers, they would fly in circles, make great loops in the sky and laugh out loud. Guided by Lucía, they were not afraid and often flew as far as The Great Bear or the Polar Star. When the little ones became sleepy, Lucía brought them back home where they landed safely in their beds.



**Three** mornings a week, Marina would load Lucía's buggy into the back of the car. With their schoolbags, the boys would race each other to be first into the car. "Lucía will be first!" Marina would always say.

She would wrap Lucía in her blanket and put her in her car seat. Ángel would sit beside Lucía and place her legs on his lap. Marco always sat in front in his car seat. Off to school they would go. The boys were dropped off at the village school where smells of the countryside now changed to those of pencils, letters and numbers. For Lucía at her school, there were new smells of paper, paint and glue.

They used a ramp to reach the school entrance where Lucía's friends waited for her. She was in the "Clouds" class. There were curtains at the door that tickled your face as you passed through and the floor was covered in soft mats. There were coloured cushions everywhere.

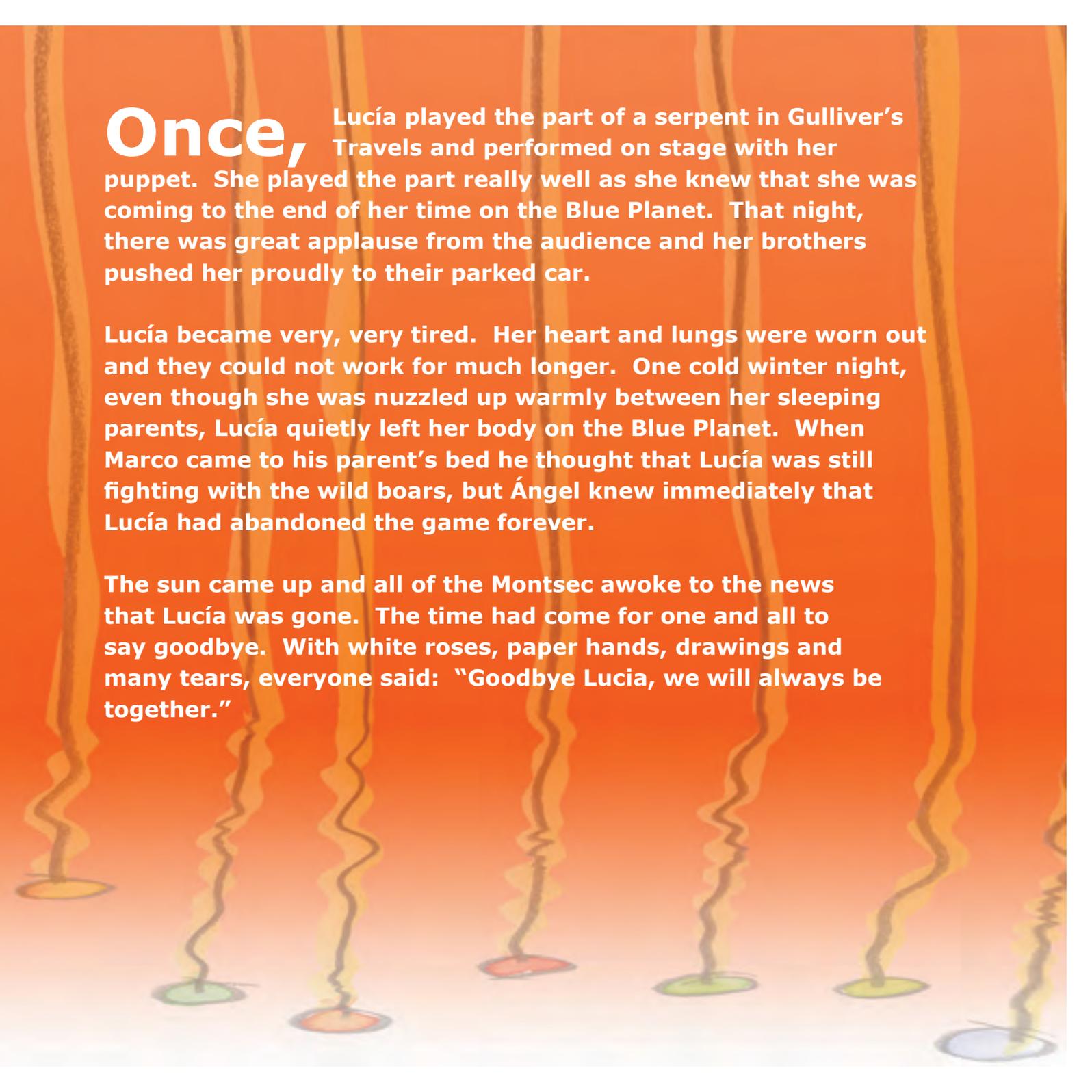
Some days, Lucía had fun painting with her hands and feet. The teachers helped her experiment and they often added things like leaves, coffee, flour or pebbles. Other days she would swing backwards and forwards and even fly over clouds. Often she was in a train, in a car or sometimes moving on top of a slow and steady snail. But she was not dreaming - she was actually working and doing her exercises. Afterwards, she could touch and feel the vibrations of the electric juicer as they made her a juice drink. It was delicious and with a little sugar, even better. They also had sports activities. Dressed in her school tracksuit, Lucía joined in every race with her speedy little wheelchair.



**Once,** Lucía played the part of a serpent in Gulliver's Travels and performed on stage with her puppet. She played the part really well as she knew that she was coming to the end of her time on the Blue Planet. That night, there was great applause from the audience and her brothers pushed her proudly to their parked car.

Lucía became very, very tired. Her heart and lungs were worn out and they could not work for much longer. One cold winter night, even though she was nuzzled up warmly between her sleeping parents, Lucía quietly left her body on the Blue Planet. When Marco came to his parent's bed he thought that Lucía was still fighting with the wild boars, but Ángel knew immediately that Lucía had abandoned the game forever.

The sun came up and all of the Montsec awoke to the news that Lucía was gone. The time had come for one and all to say goodbye. With white roses, paper hands, drawings and many tears, everyone said: "Goodbye Lucia, we will always be together."



**The first** thing the princess did when she got back to her planet was to run to her father and throw herself into his arms. Looking at his longed-for daughter, the king noticed the sadness in her face. The princess said to him, "Papa, it's very nice to be back home with you but I miss everyone so much."

"It is completely normal when you have been so happy with them", replied her father. "Don't be sad my princess, because you will live on, in them. They will remember you when they smell the flowers, when they look at the stars at night, when they see the blue of the ocean and the sky that you loved so much. At home, at school, in the Montsec, even in Holland.....everyone will smile when they think of you and continue to feel your sweet silence.

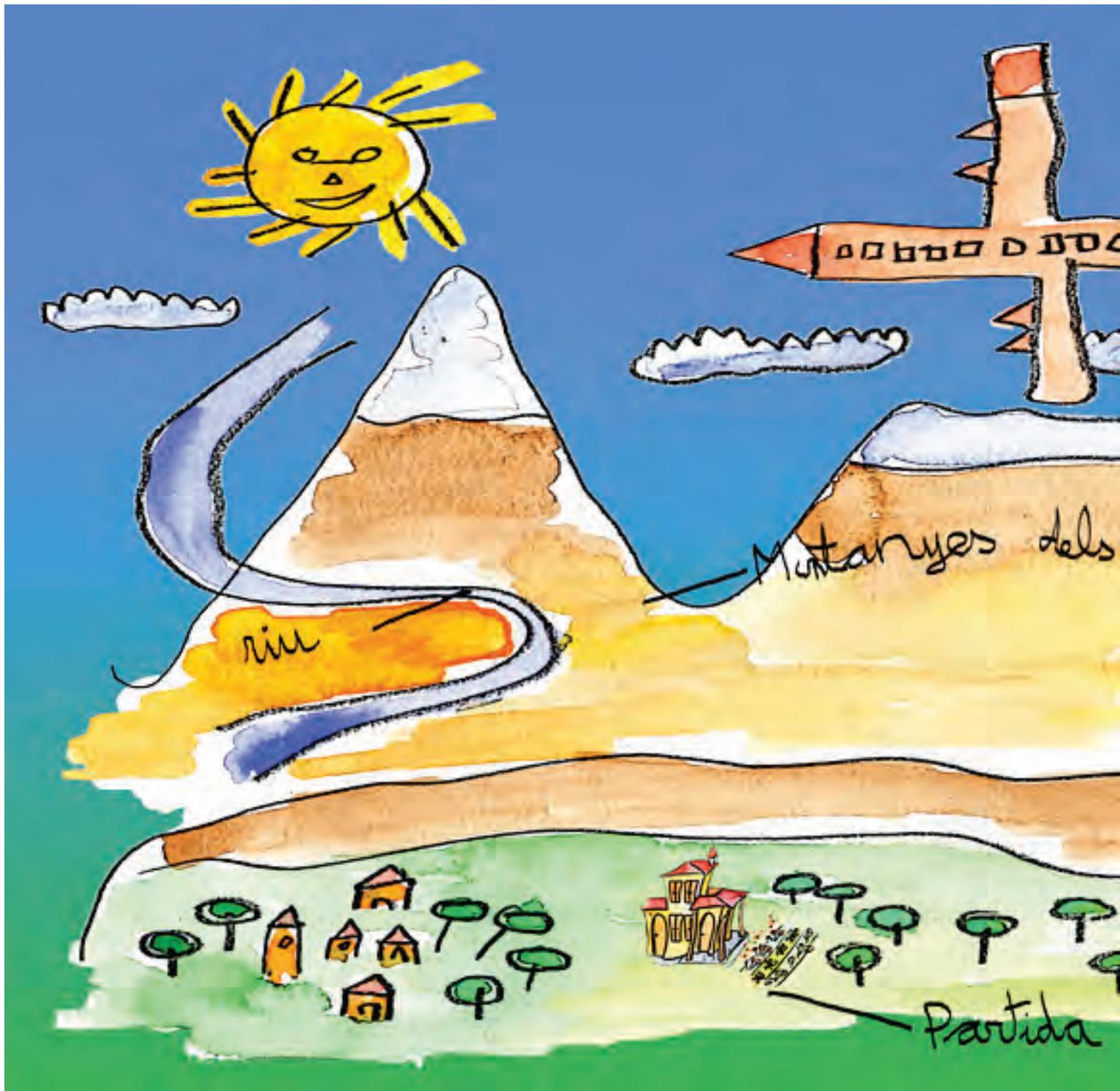
Her father's words brought a huge smile to the princess's pretty face and she began to tell him all about her brothers. "They were my best friends. I let them run races with my special chair but when I was not feeling well, they let me sit quietly and took care of me. And the most important thing was, they learned how to be patient and wait.

**Without** taking a breath, she talked about her schoolfriends, about the school excursion to her parent's farm where they saw the goats and tried some goat's milk, about the African drums that made her heart pound with vibration. She became a little sad as she added, "but in the street it was different. People looked at me strangely. They turned their heads to stare as I passed by. Do you think they knew I was from another planet?"

The king replied, "They surely did not understand how much you enjoyed flavours, smells, sunlight, fresh healthy air and above all the company of those who loved you. You have experienced great things my princess and because of that, this will be the last time I will call you by that name."

Then the king took off his golden crown and placed it with great pride on his beautiful daughter's head.

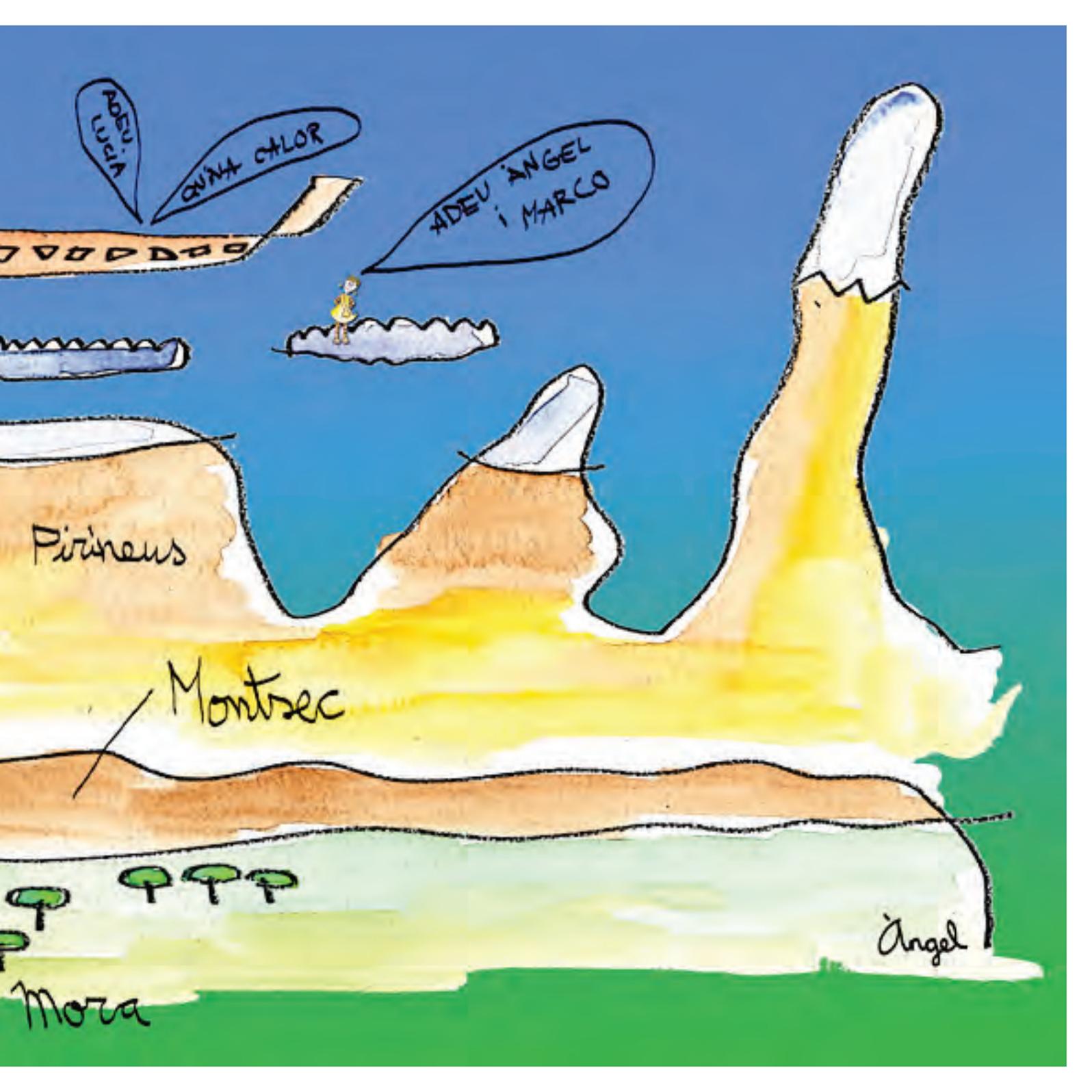




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Montañas del

Partida



ADEU  
LUCIA

QUINA CALOR

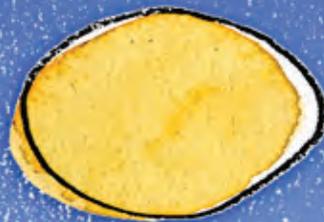
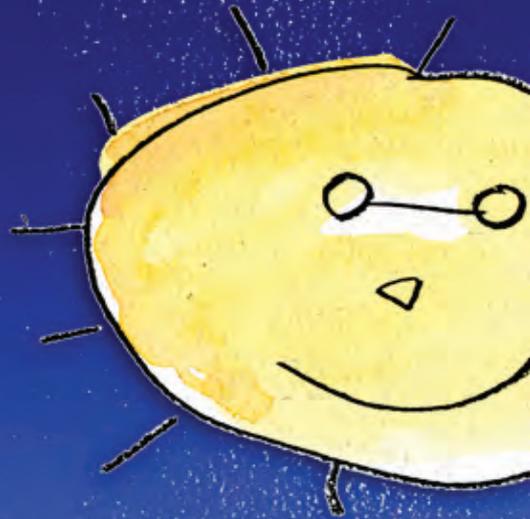
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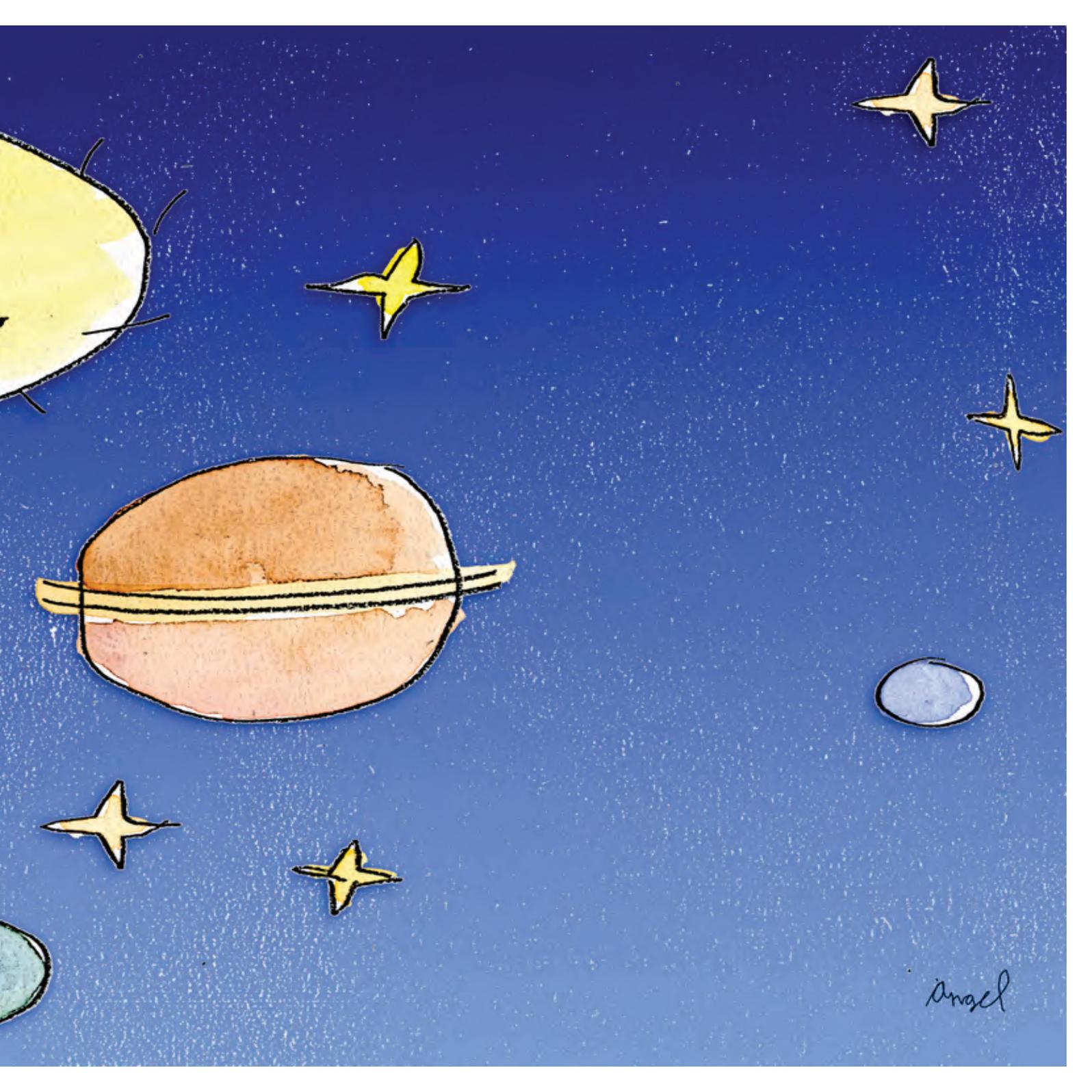
Pirineus

Montsec

Moza

Angel





Angel



Here is Lucia!