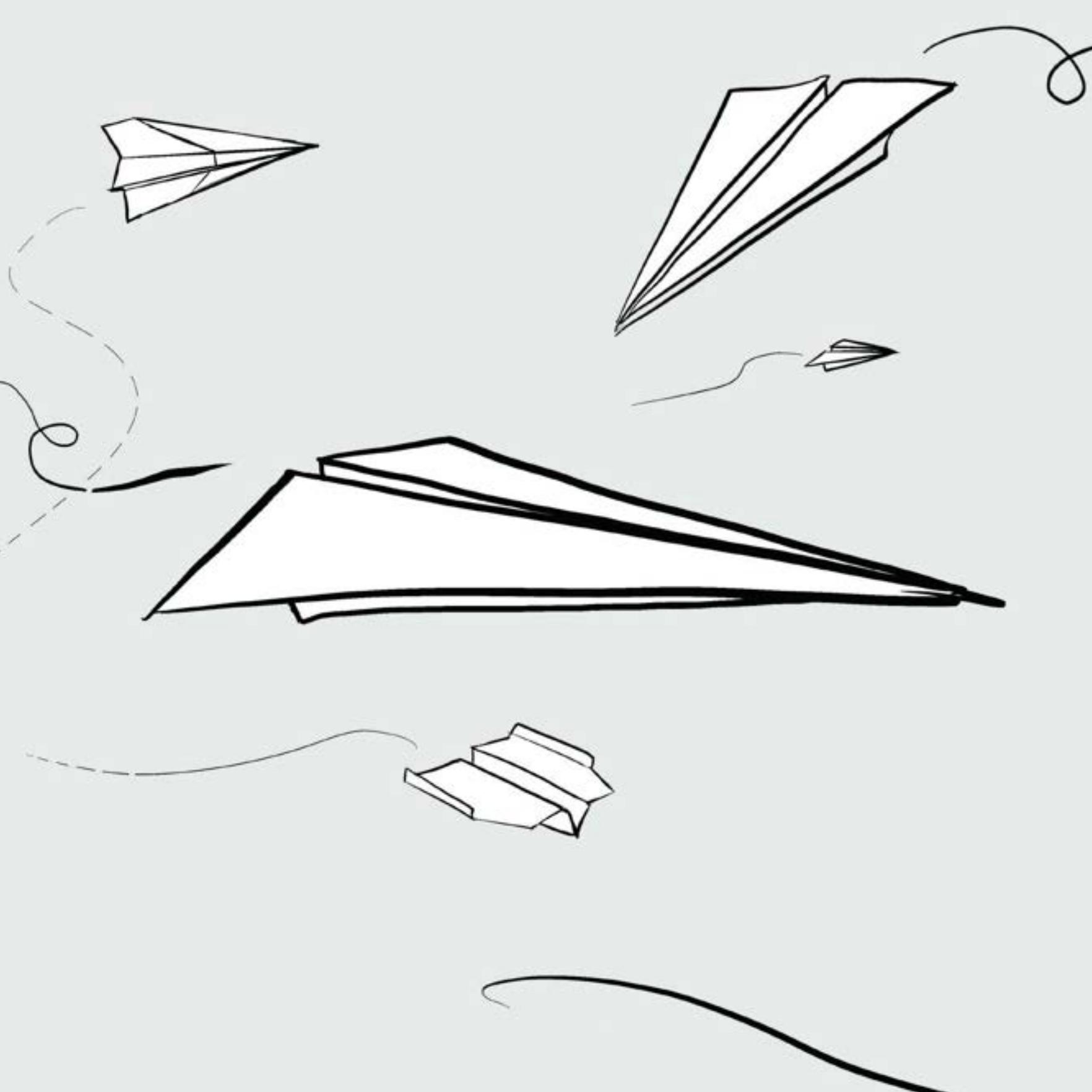
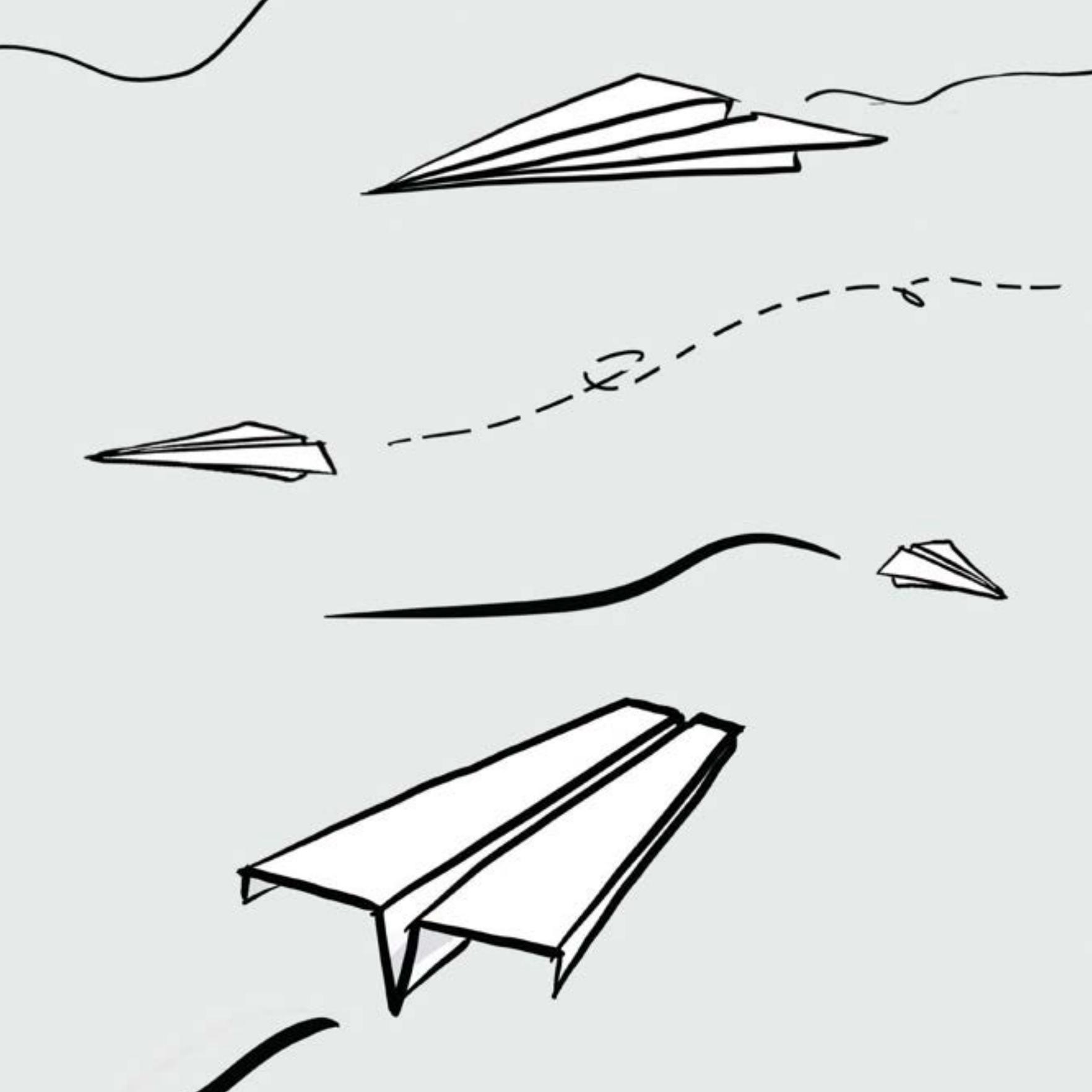


Discovering the world with **DANIEL**

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Translation: Anna Arias Fuentes







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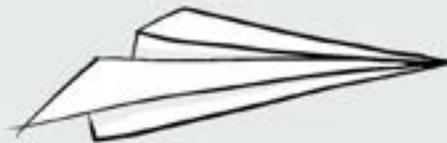


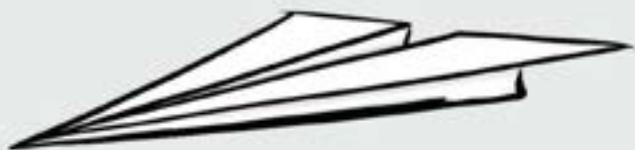
Hemiparesis during infancy

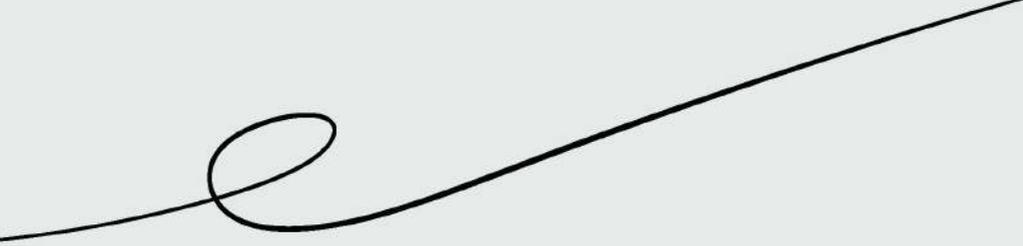


To all those children affected by hemiparesis and to the people who go through this journey with them; parents, family, friends, teachers, professionals and society in general.

To all the people who wish to learn more about the realities of this condition that affects so many worldwide. For a near future where all children enjoy equal opportunities, respect and social inclusion.







To Guillem:

“Make it your goal every day to follow the things that you love, enjoy the journey.”

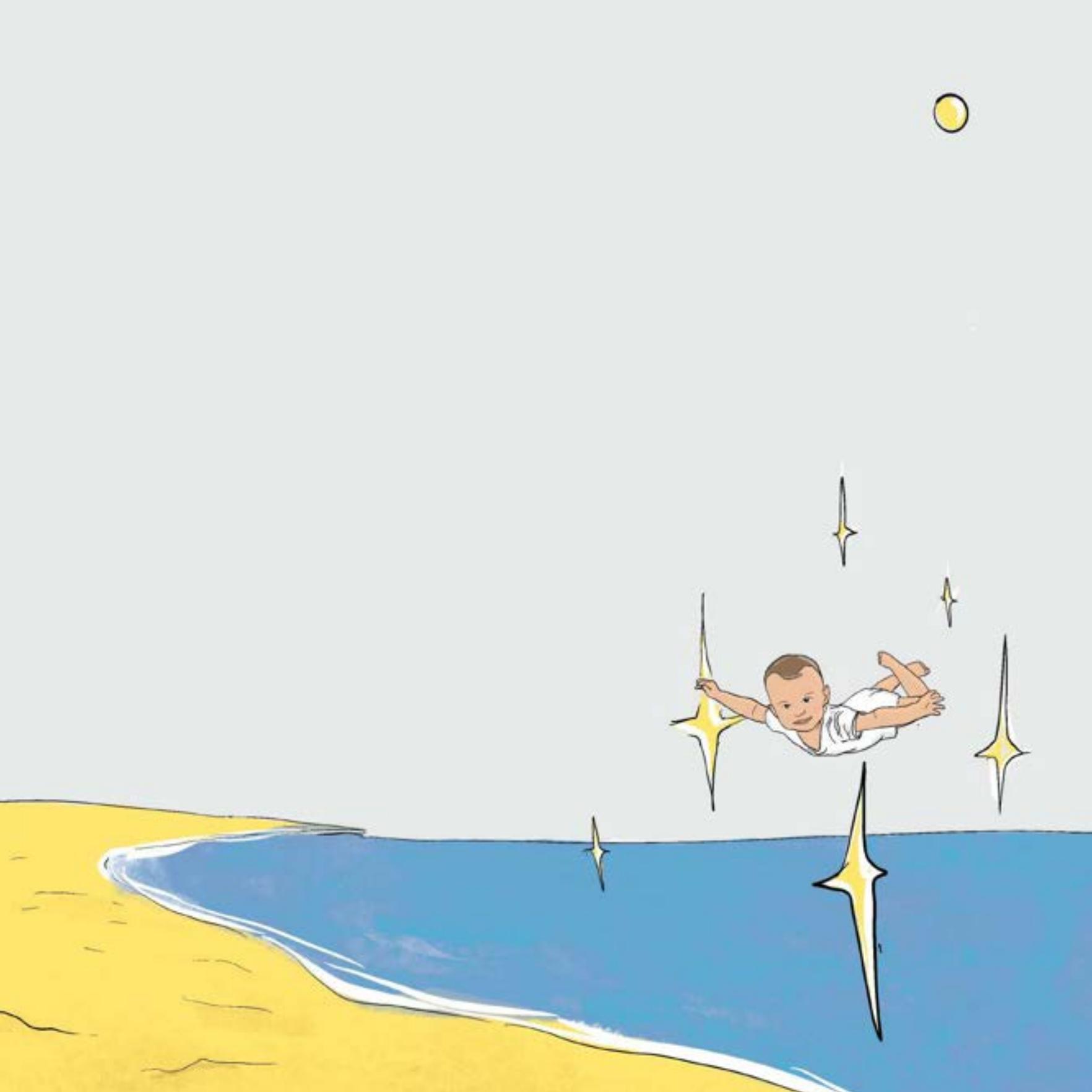
Mom

Daniel was born on a warm summer day, his parents were looking forward to meeting him.

When the moment arrived and they saw his face, the first thing that his mother thought was:

He is so beautiful!



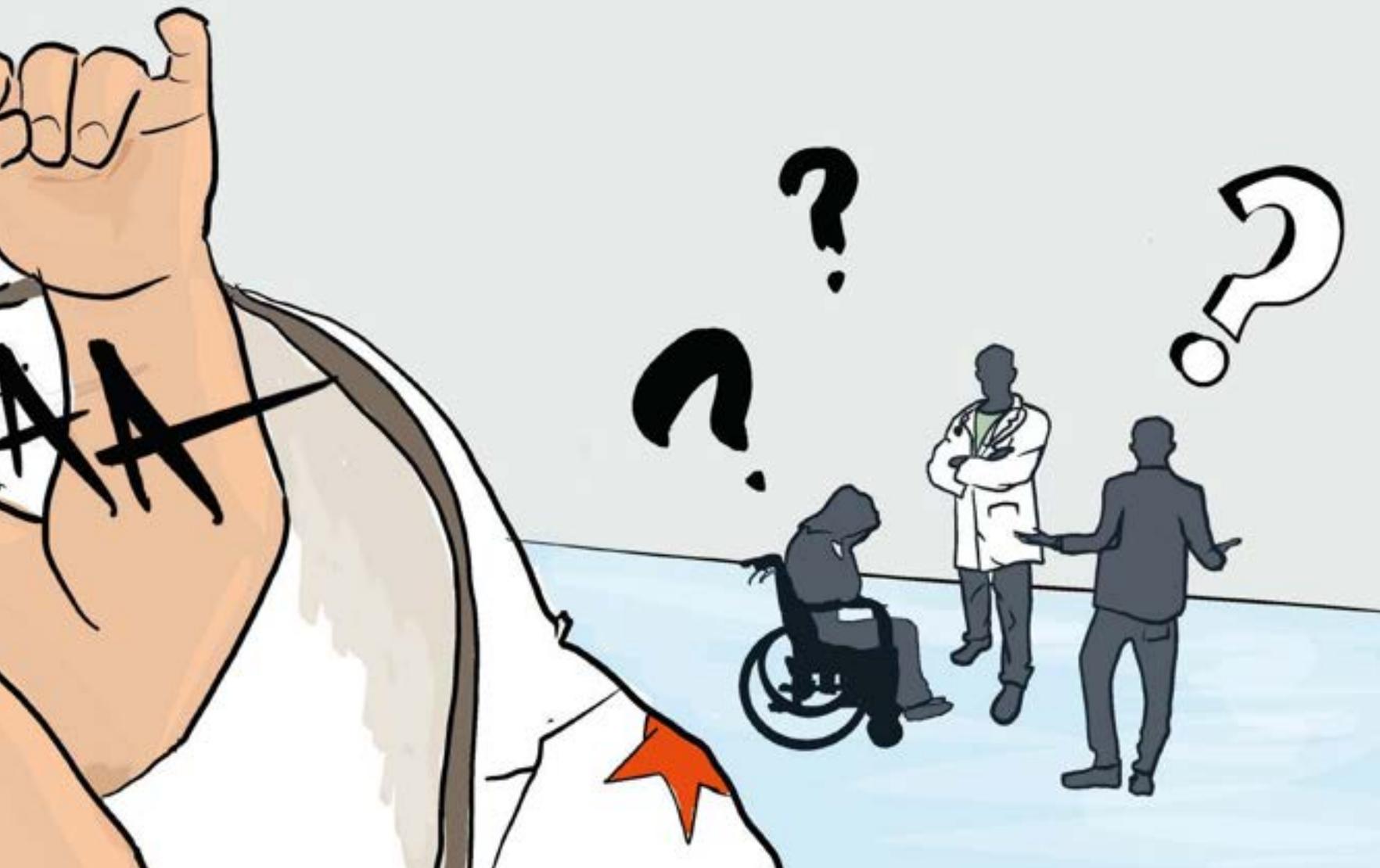




When Daniel managed to get out of his mom's belly, he cried and cried.

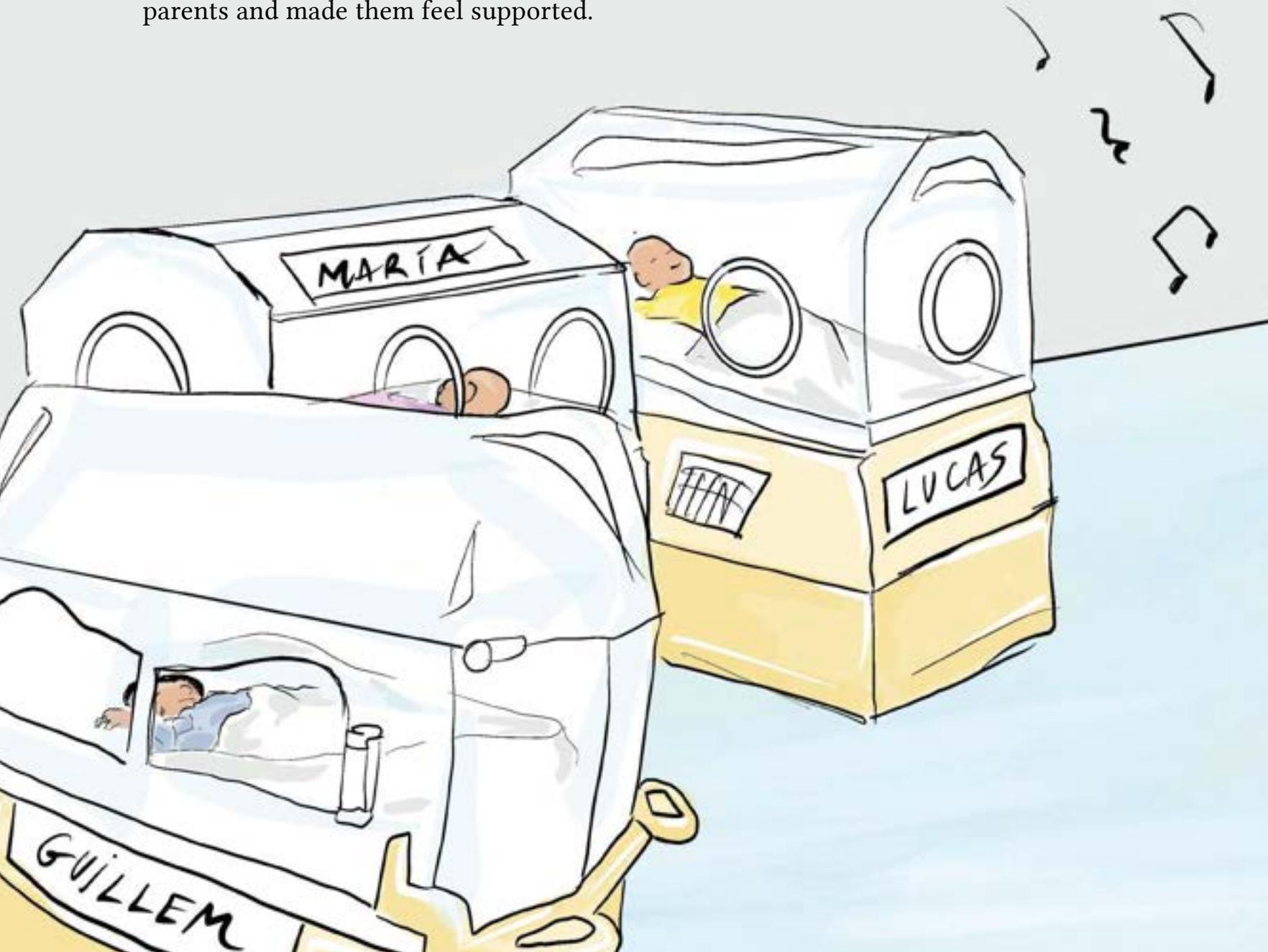
His parents were worried and asked the doctor and nurses:

—Maybe he is not feeling well? Is he in pain?
He looks very angry.



A few hours later the doctors realized that he was ill. In order to give him the best care, he was moved to a much bigger room, where he had the company of other babies and a little bed just for himself!

There, he met some loving, caring and kind nurses. This comforted his parents and made them feel supported.





Now Daniel was calm and seemed to sleep soundly.

His parents tried to be with him most of the time. They got to know his smiles and yawns. But the most important thing was that, just after a few hours of his life, Daniel showed them that he was a strong, loving and brave baby.



They hugged him and kissed him at the slightest opportunity. They sang to him, changed his diaper and checked his temperature every three hours. Yes, that often!

They explained to him everything that was happening. Ooooh! And everything that they were going to do once they left the hospital!

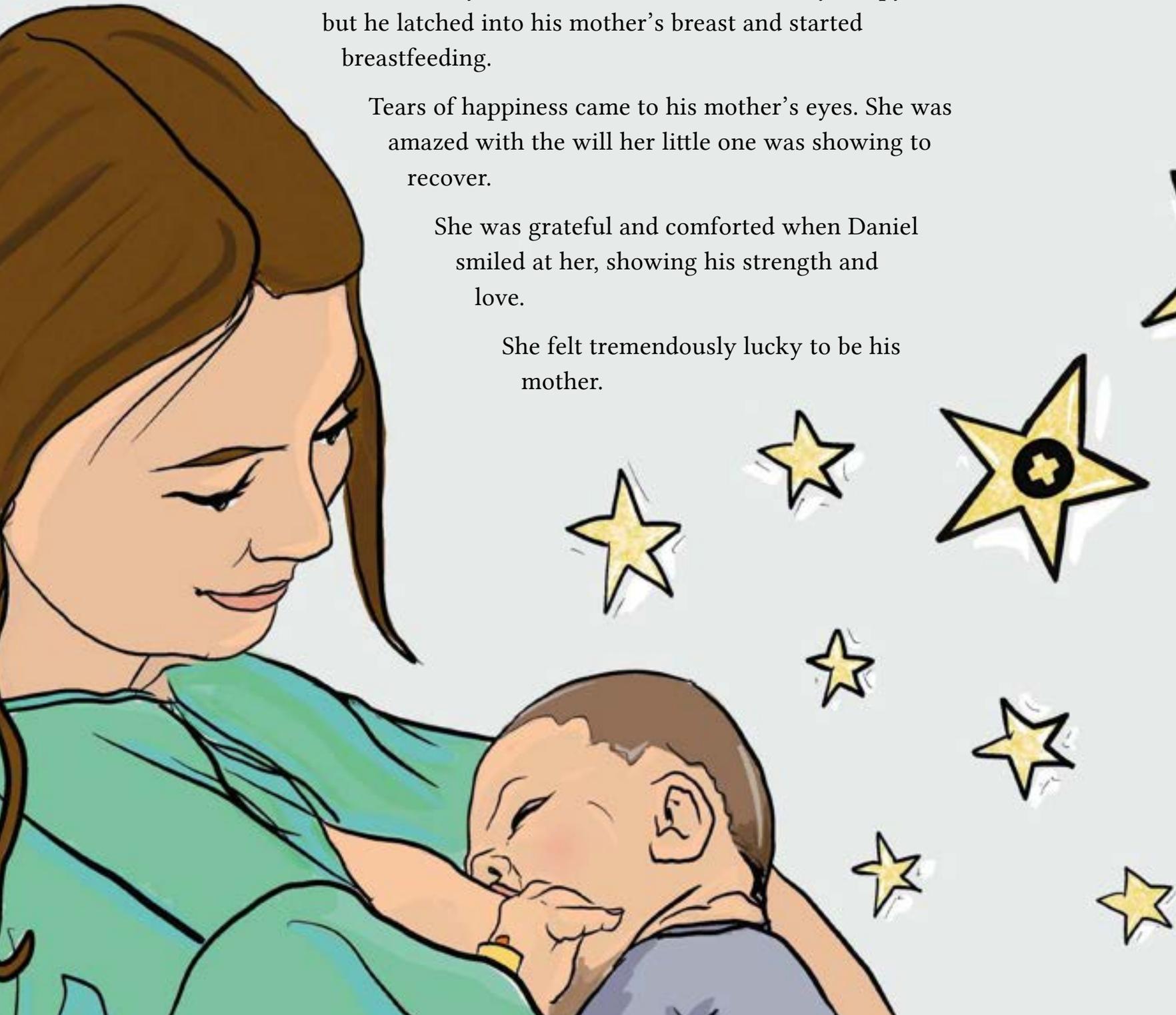


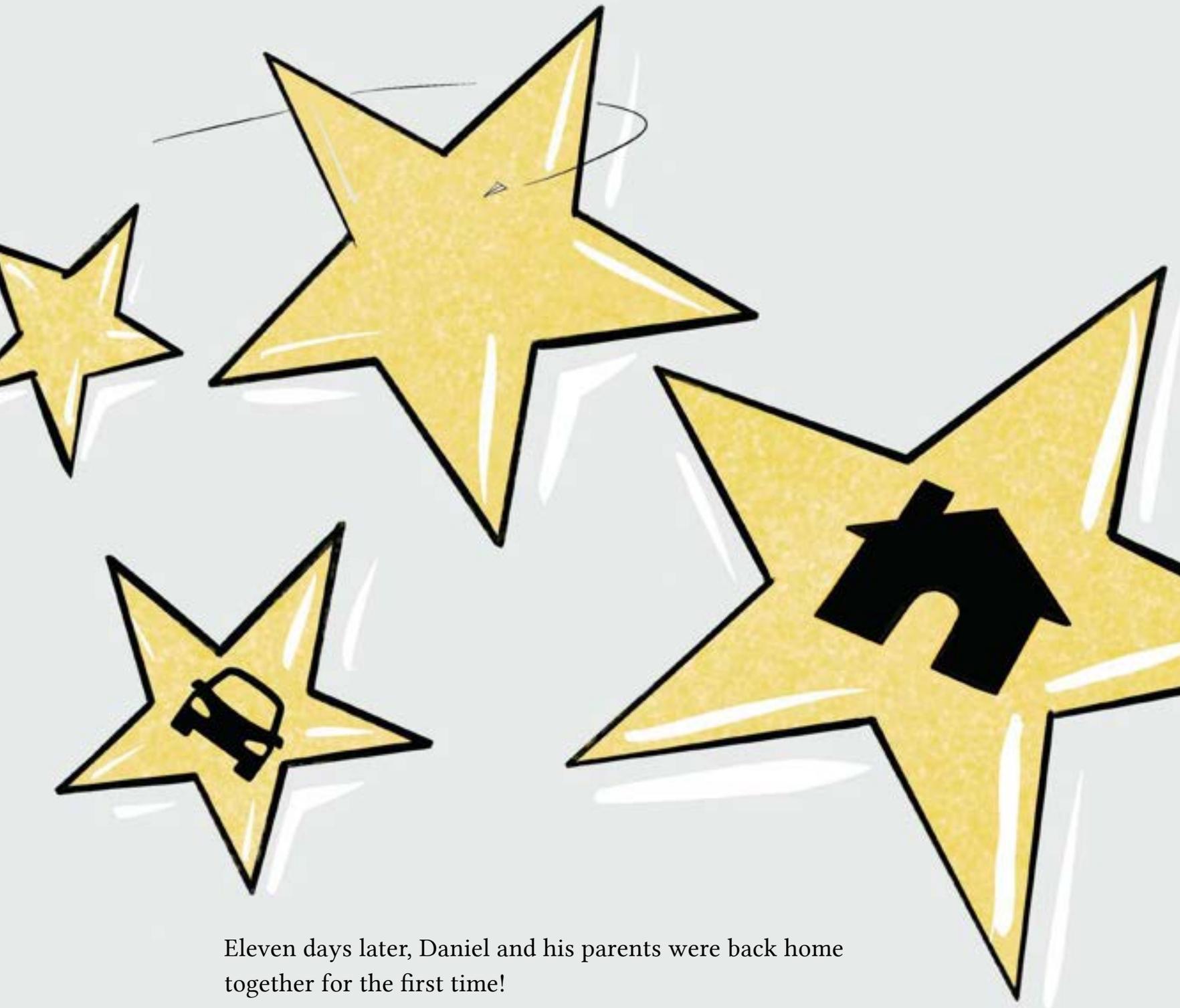
On the third day of Daniel's life, he was still very sleepy, but he latched into his mother's breast and started breastfeeding.

Tears of happiness came to his mother's eyes. She was amazed with the will her little one was showing to recover.

She was grateful and comforted when Daniel smiled at her, showing his strength and love.

She felt tremendously lucky to be his mother.

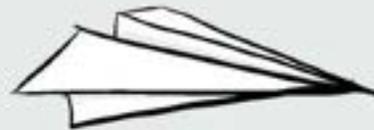




Eleven days later, Daniel and his parents were back home together for the first time!



As a result of how sick he had been when he was born, Daniel had less strength and mobility in his right arm and leg. Due to this, this side of his body moved slower. This is what doctors call 'Hemiparesis'.



Let's imagine the two halves that form the brain and how they are connected through roads.

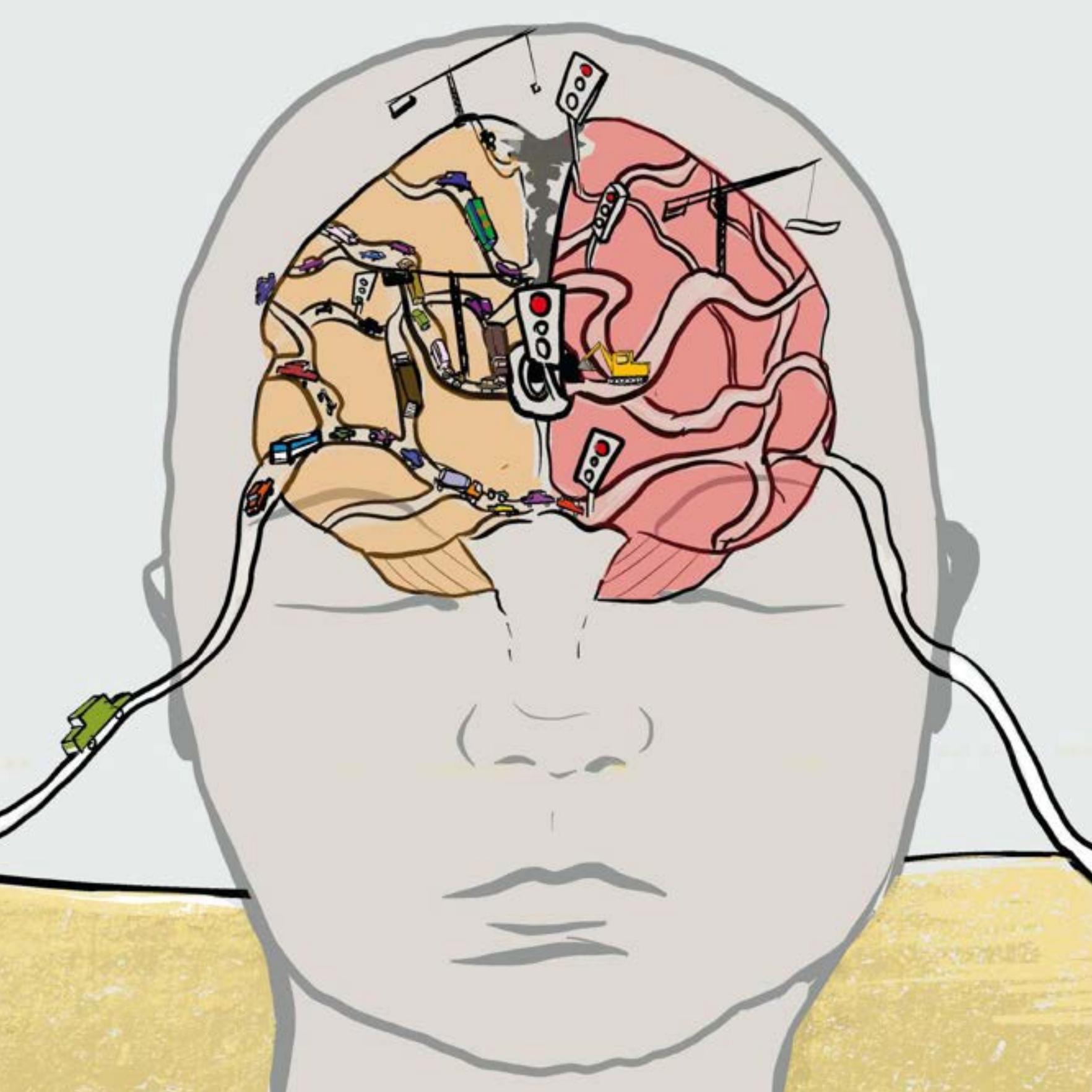
The cars could travel from one side to the other between both hemispheres, until one day a red traffic light was placed and they couldn't anymore.

The traffic light warned all the trucks, motorbikes, cars... that those streets couldn't be visited anymore, they were gone!

And so new roads, paths, bridges and highways had to be built again. And do you know who was in charge of making such an effort and doing all this work?

Daniel





To increase his ability to feel and recognize the right side of his body, his parents massage him and touch Daniel's skin with different fun objects every day.

They put bracelets with bells on him or help him to hold a maraca and have fun singing.

While his mom sings his favorite songs, she walks her fingers through his arm in fun ways. Sometimes it's as if her fingers were little ants and other times it's as if they have big steps like an elephant. They say hi to each of his fingers and dance to mother goose rhymes.





Serpentine



Silk
handkerchiefs

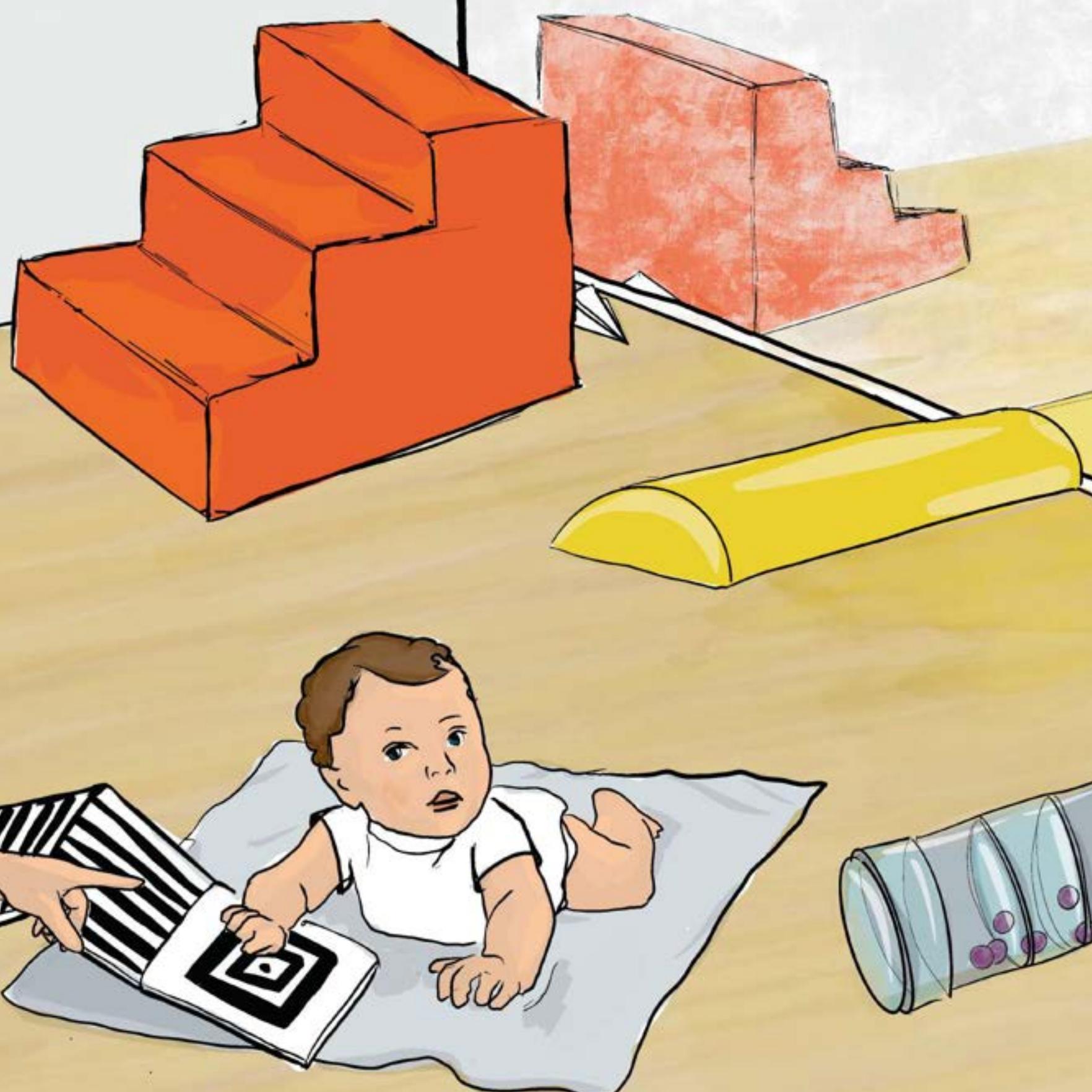
They can see changes
every day that passes by!

Daniel looks at his right hand for the first time.
With the help of his other hand, he is able to bring
it to his mouth. And after a few months, he is able
to scratch his face when he is sleepy.

A few days a week, Daniel with his parents go to visit Sara, his physiotherapist.

She plays with him for a long while and takes the opportunity to show him new ways of moving. She also teaches his parents how to help him to keep practicing at home.





Daniel has problems looking at his right side. His parents decorate the wall of his changing station with big colorful butterflies to increase Daniel's curiosity towards this side. He loves looking at them!



They change the position of his crib so he has to turn towards his right to look at his mother when she talks or sings to him before bed time. They do the same with his car seat or during lunch time. One of his parents is always sitting to his right side.

When it is time to have fun, anytime that Daniel is not sleeping, his parents place all his toys towards his right. They know that this is hard for him, but this way Daniel gets to know more about this part of his body.

Daniel, who is a smart boy, moves them whenever he gets a chance! He likes to play more with his little left hand, it's easier for him.



Today our little hero has a headache. It is as if a storm with thunder and lightning is happening in his brain. This makes him feel tired and he cries often.

Daniel has epilepsy, his parents are worried and sad.



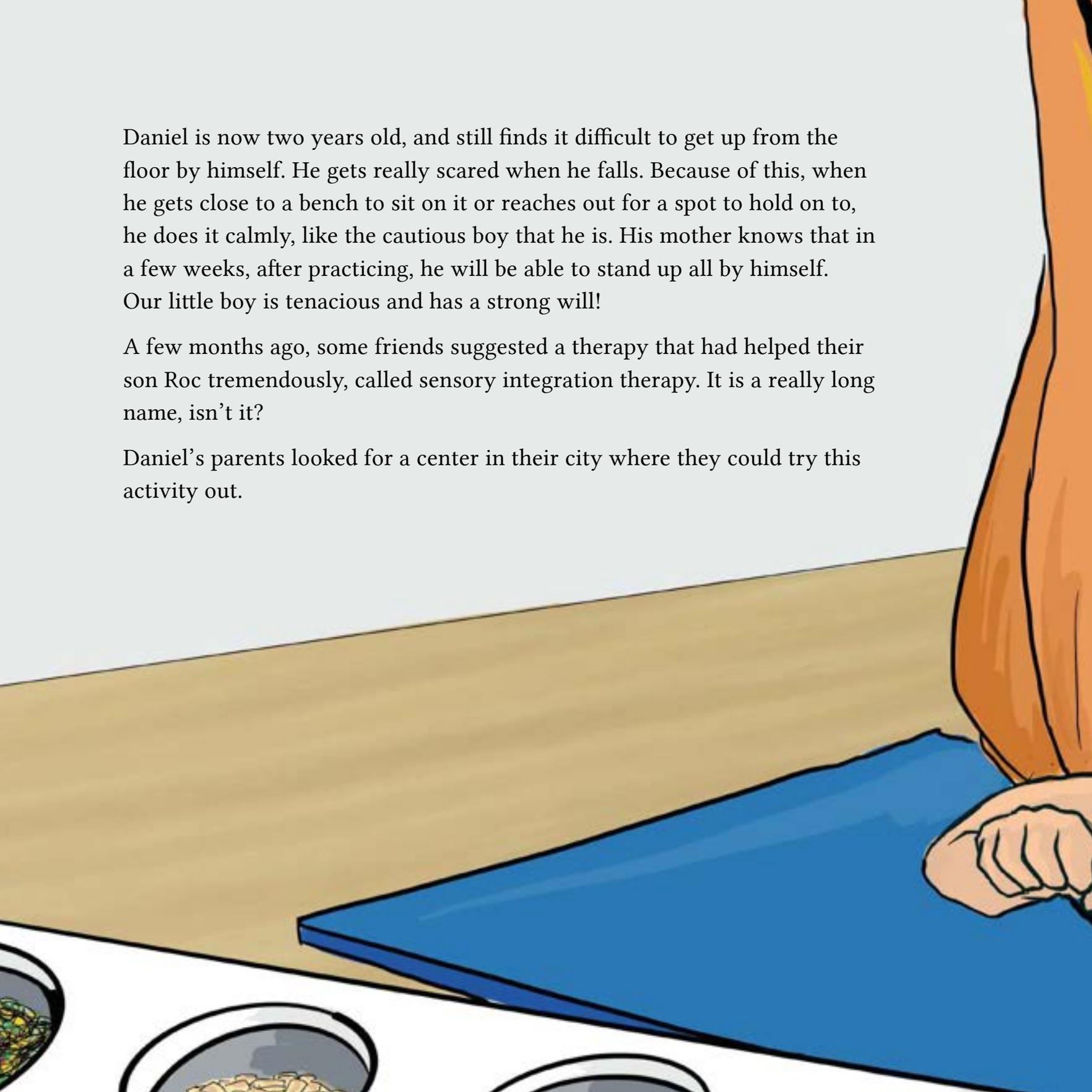
The neurologist gives him medicines that help him control his seizures. Slowly they seem to take effect and make the seizures disappear. With this, happiness and calmness slowly return to the family.



Daniel is now two years old, and still finds it difficult to get up from the floor by himself. He gets really scared when he falls. Because of this, when he gets close to a bench to sit on it or reaches out for a spot to hold on to, he does it calmly, like the cautious boy that he is. His mother knows that in a few weeks, after practicing, he will be able to stand up all by himself. Our little boy is tenacious and has a strong will!

A few months ago, some friends suggested a therapy that had helped their son Roc tremendously, called sensory integration therapy. It is a really long name, isn't it?

Daniel's parents looked for a center in their city where they could try this activity out.



This center became a very special place for Daniel. He has a lot of fun there! Especially when they swing him on the hammocks and the swings that are hanging by the ceiling.

They also throw balls and hoops into a bigger hoop. Sometimes they also touch toys and objects that produce strange sensations to Daniel. Or that's what it seems from the looks on his face! At the beginning he doesn't want to touch them but after a while, he starts to like some of them!



Oh! There is one thing that I have not explained to you yet! It might sound a little strange to you... it was definitely strange to Daniel's parents when they heard about it for the first time.

One day, a doctor explained to them the possibility of helping the little one with a therapy called 'Constraint Induced Movement Therapy'. It sounds a little odd, doesn't it?

It consisted of making Daniel wear a body, like the ones that we wear to stay warm. But this one is special; it only leaves one arm free! Just the one that he needs to train.

After a lot of thinking, his parents decided to give it a try. If it helped a lot of children, and they learned to move their little hands, maybe it could help Daniel as well.



ONLY
ONE HAND!

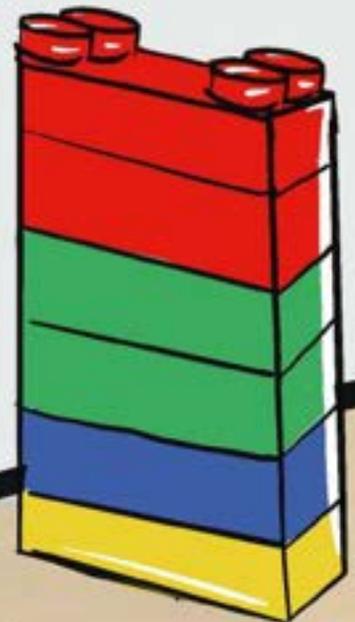


CIMT!

The truth is that it was hard at the beginning. Sometimes Daniel seemed happy, and he took part in the games but other times he was tired and even got angry. His parents know that to move his little hand is really difficult and requires a lot of concentration. Because of this they chose to practice short periods at different moments during the day. After a few weeks, they started to see how Daniel was able to destroy toy towers, touch their faces and eat cereal!!

When his parents saw his achievements, they were overjoyed!! They are really proud of him; they always cheer him up and recognize his willpower.

But do not think that they do this therapy every day! Nooo! They only do it once in a while. They practice for a few weeks and then they rest for a few months!!





What they do every day is to find moments to play using both hands. Daniel's parents know that his right hand doesn't learn easily, and they try to repeat activities the little one loves. They open his case and take out some surprise his dad has hidden inside, or they uncap markers to paint pretty drawings on the wall.

Daniel loves the taste of his toothpaste. He strives to remove the tap and squeeze the paste out onto the toothbrush.

When he goes to buy groceries with his father, he places his two little hands on the handle of the shopping cart. He pushes it really proudly going through the aisle of the supermarket. When his right hand can't take it anymore... he lets it go! Daniel asks his dad to put it back in place and they keep filling up the shopping cart.



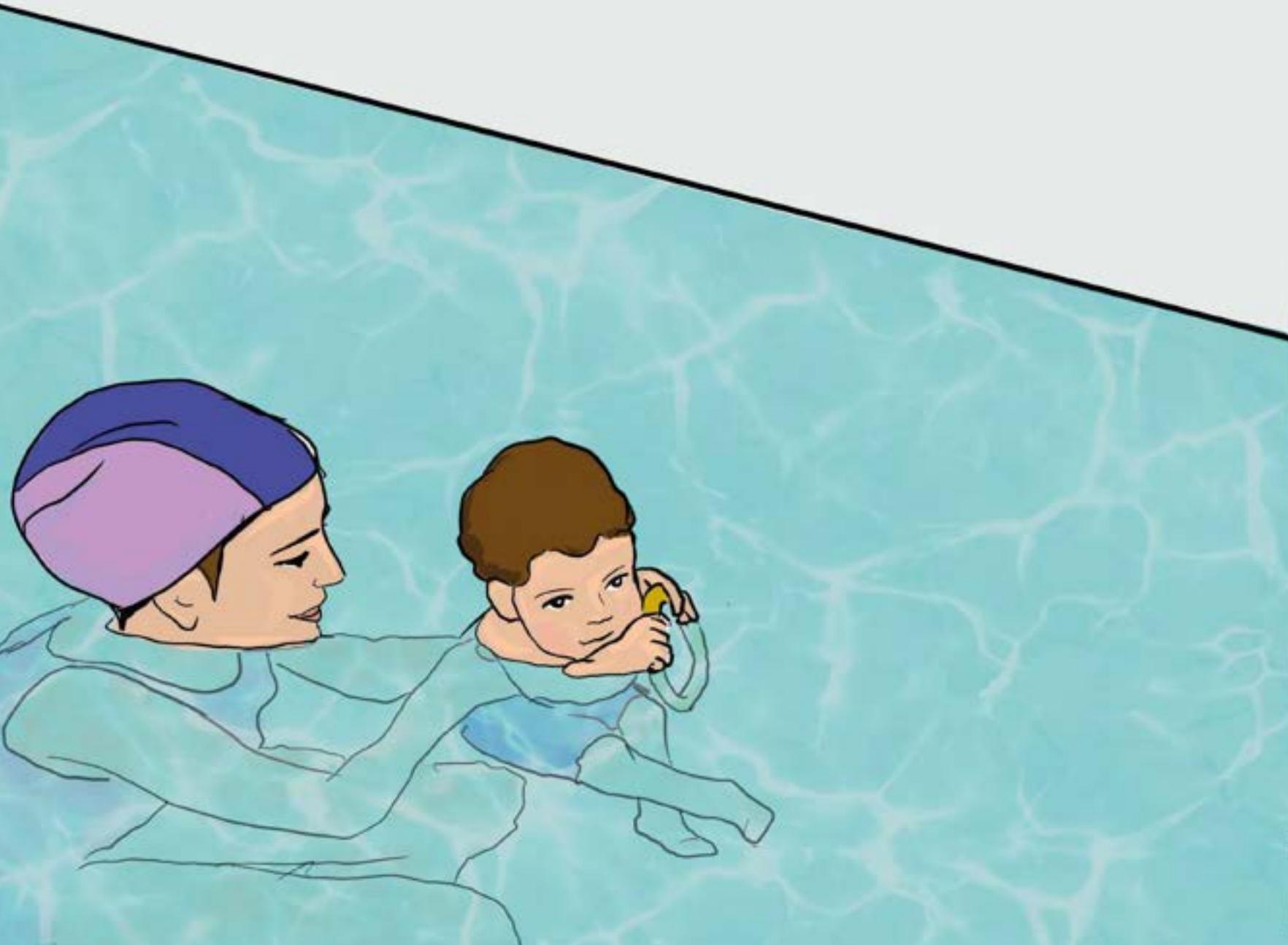
The little one loves to put clothes inside the washing machine, and his parents take advantage of this. When they tidy up his room, they place pieces of clothes on both of his arms and he brings them happily to be washed.

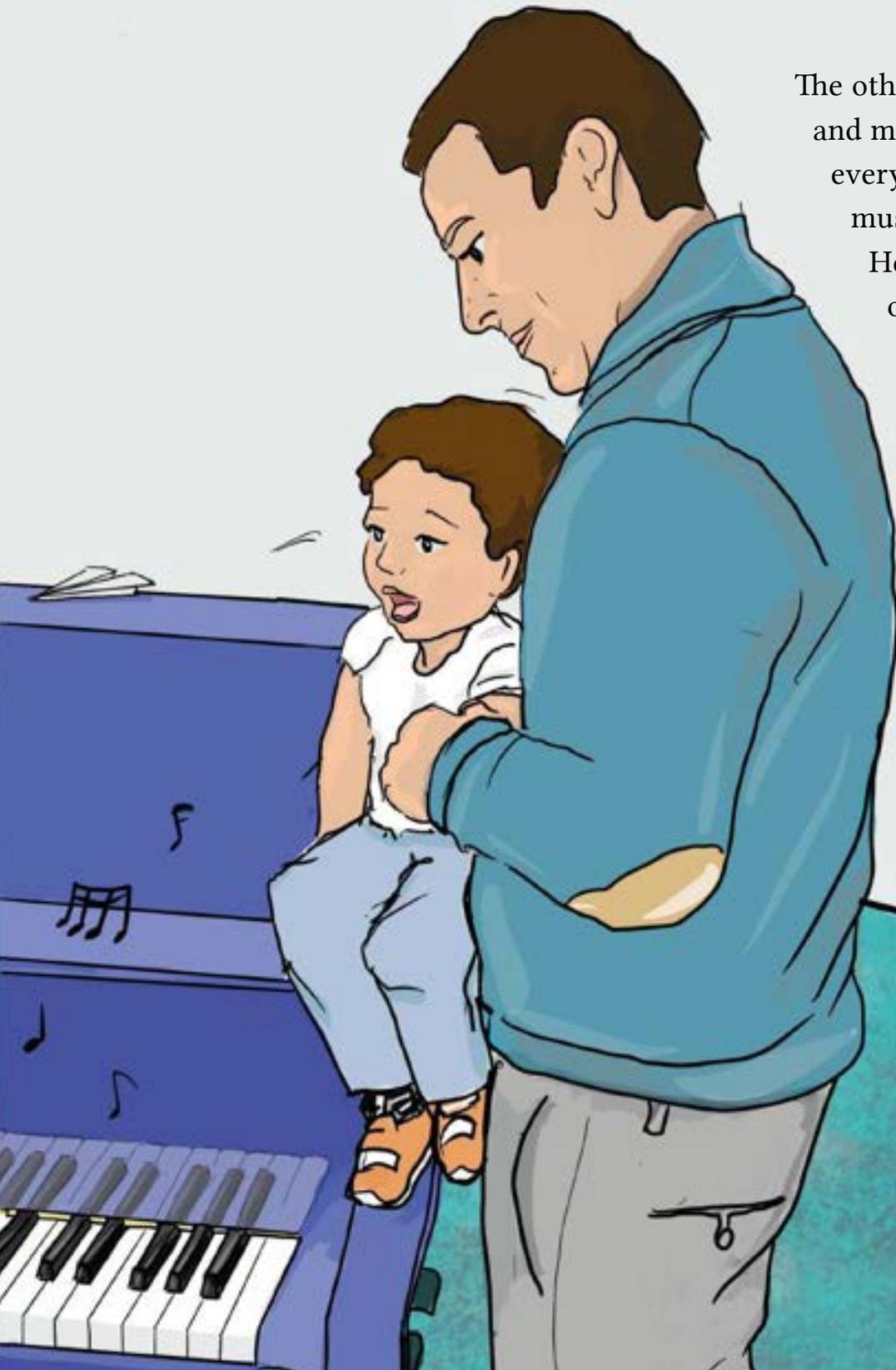
He enjoys it a lot when he goes to the playground with his grandparents. He plays on the swing and now he can hold himself onto it using both hands!



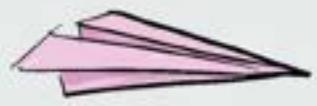
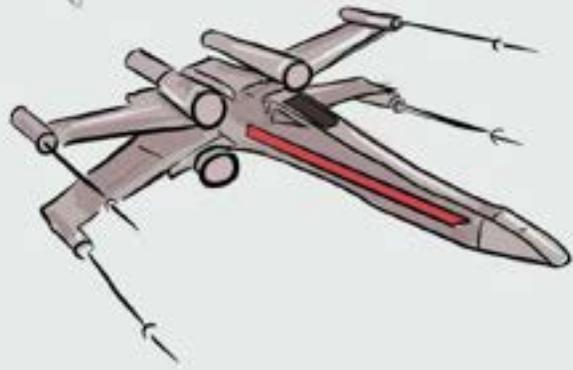
Daniel's parents love to share two activities with him.

One is to have a swim in the swimming pool! His mother loves it, Daniel...
some days more than others!





The other one is to go to concerts and musical workshops! They go every week. Daniel looks at the musicians as if he was hypnotized. He swings from one side to the other following the rhythm of the music with a smile. He loves when they let him play instruments and dances while being in his mother's arms.





A few years later...



Today while leaving music school, Daniel explains to his mother that he is worried about having to choose an instrument this year.

—Mom, I am not sure about which instrument I want to play.

—Which one do you like the most?

—The piano and the trumpet, also percussion ...

—And what do you like the most about the piano?

—It is really big!! And I like how dad plays it!! But my right hand is slower than the left one. My fingers don't move the same way. It will be harder to play songs with both hands.

—You are right honey; it will be harder to play with both hands at the same time. If you want, you can play your favorite melodies with the left hand and the right one can help make it funnier. For example, giving a clap at the end. Or you could use it to start: you choose a musical note that fits the melody and you make up the rhythm. Dooo Dodo Doooo dodo!

To introduce the song.

—You are right! I know a song that is played with a fist!! But... it is not the same. Won't be able to play Beethoven's for Elisa.

—Mmmmm... right... not exactly how Beethoven composed it... And what catches your attention from the trumpet?

—Mom!! I loved the trumpet when I heard the Combo of Latin music during the Christmas concert. The boys danced while they played!!

—I am not surprised you feel that way, it is really fun to be able to play and dance at the same time!

—There are many percussion instruments that I can play with only one hand: small tambourine, bells, rain stick... Well, if I try hard there are

more that I can play: Keys, agogo, big tambourine, shekere....

Oooh, I would love to play the surdo in a batucada! Mmmm, I am not sure if I could play all those instruments...

—The only thing that matters is that, when you play music, you are happy and enjoy whichever instrument you play.







Today Daniel's father waits for Daniel at the entrance of his school.

Daniel throws a smile at him when he sees him and hugs him. They had agreed to go skating after school at the promenade.

His balance improves every day. The more he practices, the more confident he feels.

When they are taking off their skates, Daniel asks his father why sometimes he is annoyed when people touch his right hand.

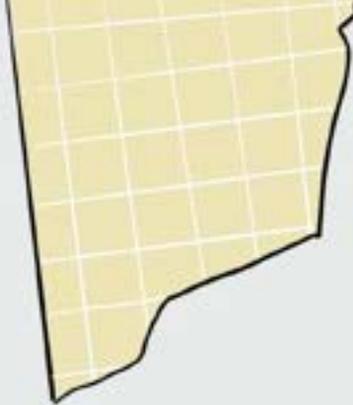
—When we have to go in pairs to the swimming pool, sometimes I don't like to hold Melisa's hand with my right hand. It is ok for a short while. But I get tired after a while, and I don't want to do it anymore.

—Love, this happens because you are more sensitive on this part of your body. We could even call it hypersensitivity. To be honest, I can't imagine how that feels. But I imagine that it is like when the tag of my t-shirt scratches my skin, and it makes me feel uncomfortable. Sometimes to the point that I can't focus on what the person in front of me is saying.

Or when the rain makes my pants wet and I have to wear them all day at work because I can't go back home to get a dry pair. It is annoying for me. I can understand that you don't feel like using that hand because it is hard for you. When I am tired, sometimes I am in a bad mood. Is it like that when it happens to you?

—You are right, Dad. When you are tired, it is best to just go to bed... hahaha

—You know that you need to work hard so your hand gets practice so it can help you. We know that your hand learns every day as long as you use it.



Today Daniel went to basketball practice for the first time. The other kids had a lot of questions when they saw that he was grabbing the ball with his hand clenched into a fist. They asked so many questions that when he met his parents after practice, he asked them why his little hand didn't make it as easy as it was for the other kids.

His parents looked at each other and said:

- Daniel, everybody has difficulties, but not all of them are easy to spot. Some are skilled in sports and others in art.
- Your father builds some crafts that I can't even imagine in my head. And I am better at other things, like singing.
- We have been wanting to propose something to you for a while now... Would you like the three of us to write a story? We could start today if you would like! On each page we will write a sentence about all the things that you have learned since you were born! Because for us, it was difficult as well to understand what hemiparesis entailed.

So they started writing...



We have learned to
be brave in life.

Mom

The brain is a mystery and
learns in many ways.

Dad

We all have strong and weak spots.
I am great at swimming, singing, making
puzzles, dancing, ...

Daniel

I choose to be happy, at least for a while, every day.

Dad

Thank you for all your hard work
and perseverance. Today you are
able to grab the ball with both
hands. Champion!

Mom

Difficulty doesn't
have to be a synonym
of impediment.

Mom



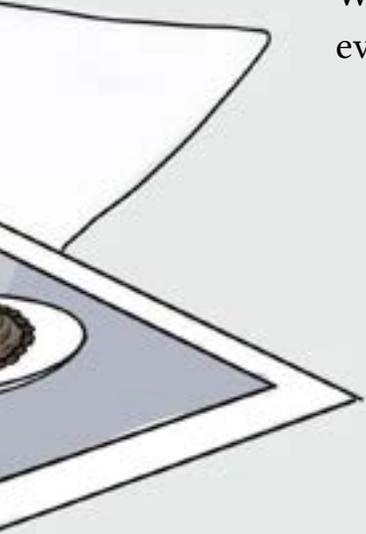
Daniel, we would like you to always try to make your dreams and wishes come true.

You transform the difficulties that you encounter in life into opportunities to learn and improve.

You have become the person that you are because of these. You are a fighter, serene, thoughtful, tenacious, hard worker and you have an amazing ability to overcome everything, that makes us thrilled every day.

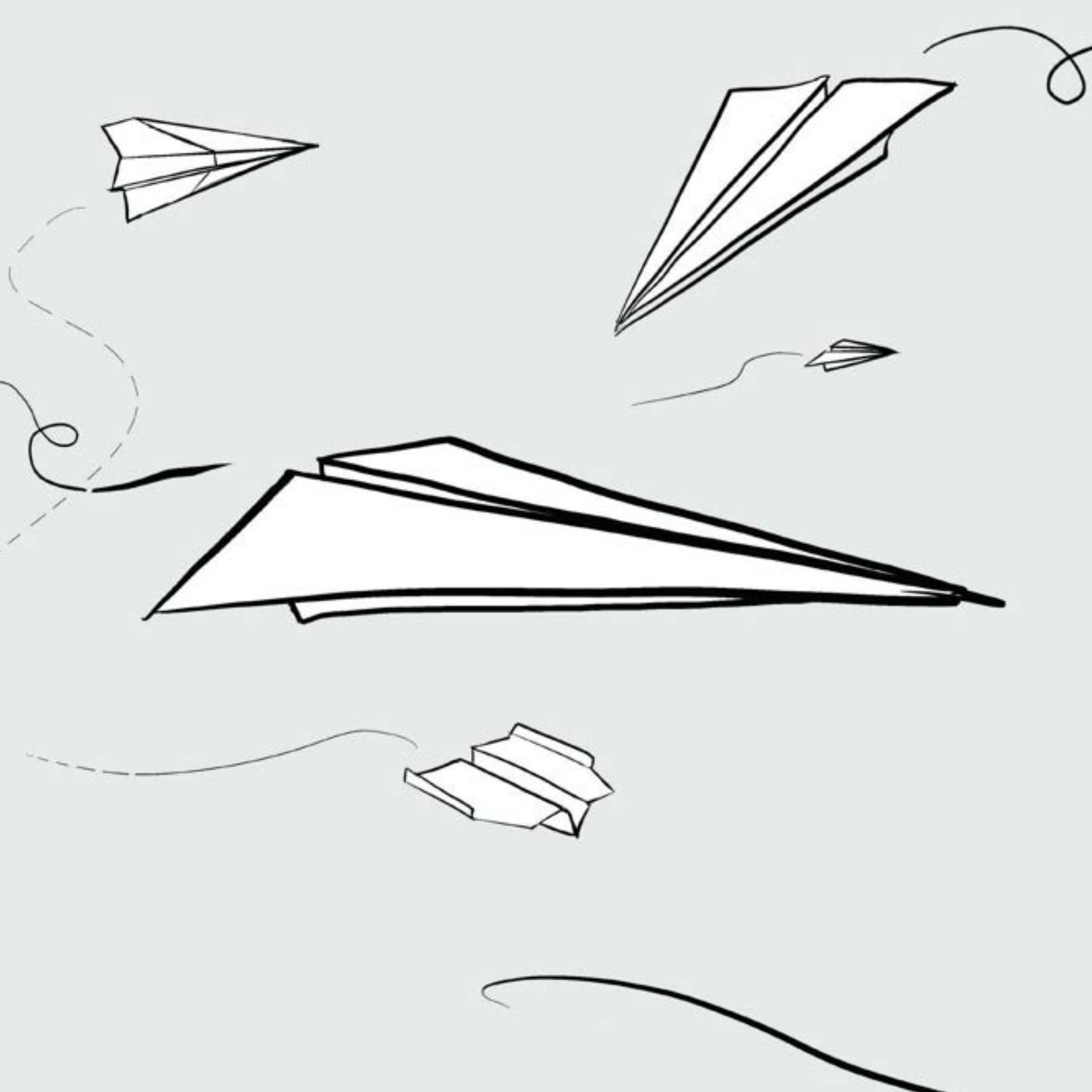
We love you and we are grateful for the opportunities that you give us every day to learn and improve together with you.

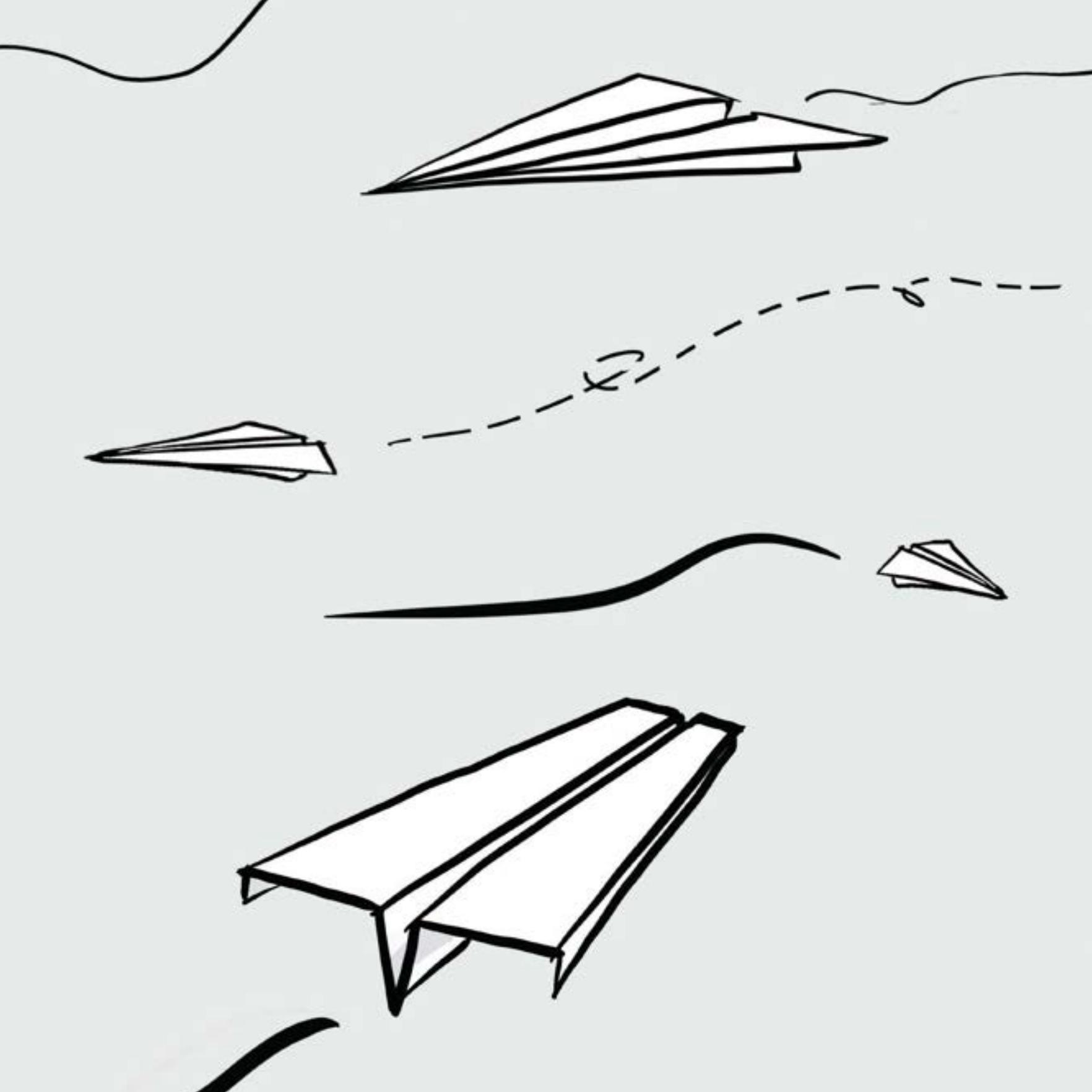
Your mother and father













Help us to take action to improve the care that is provided for newborns with neurological problems and their families

<https://www.neurologianeonatal.org>

