Starry Skies, Cosmic Shakes

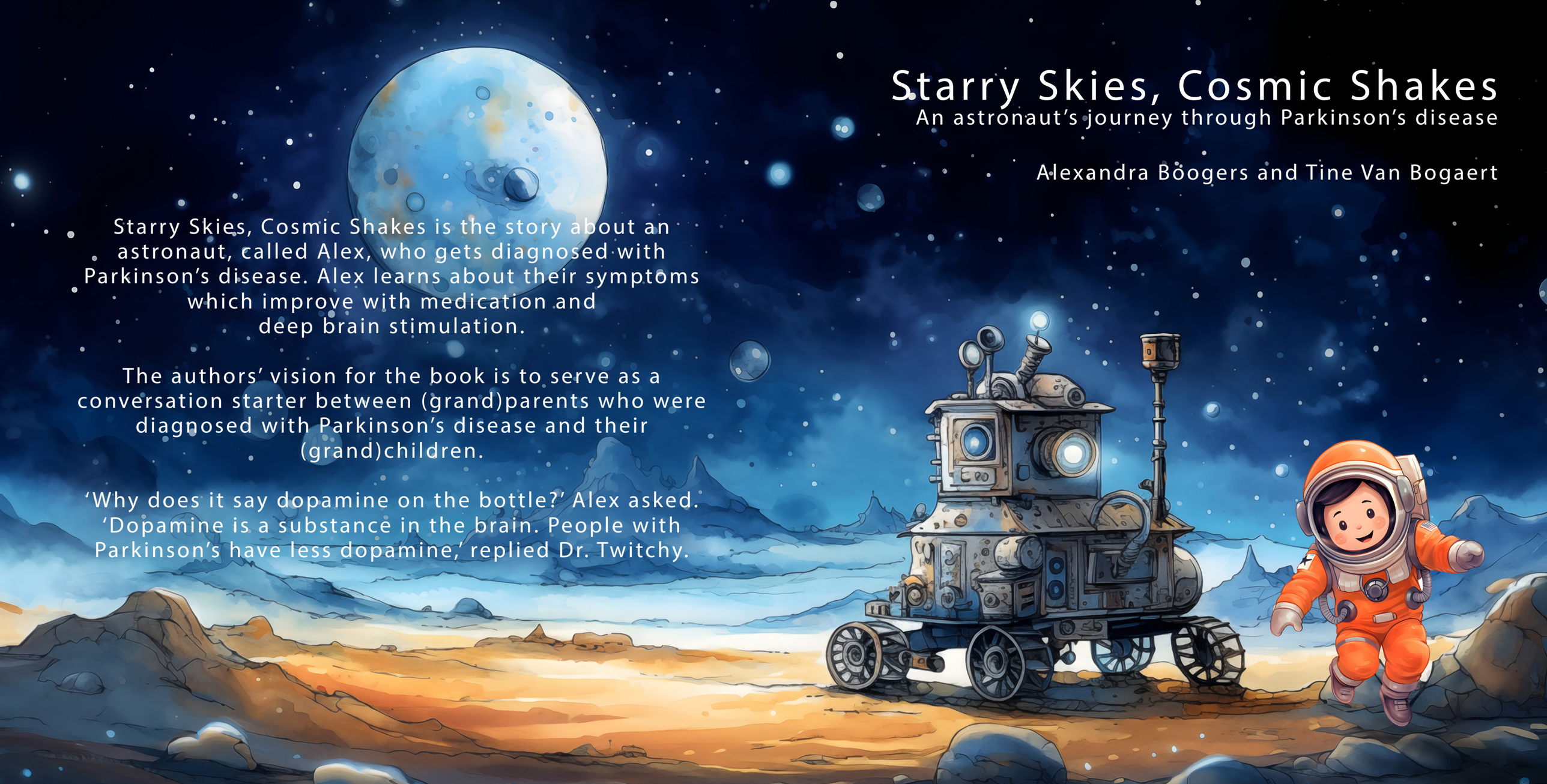
An astronaut's journey through Parkinson's disease

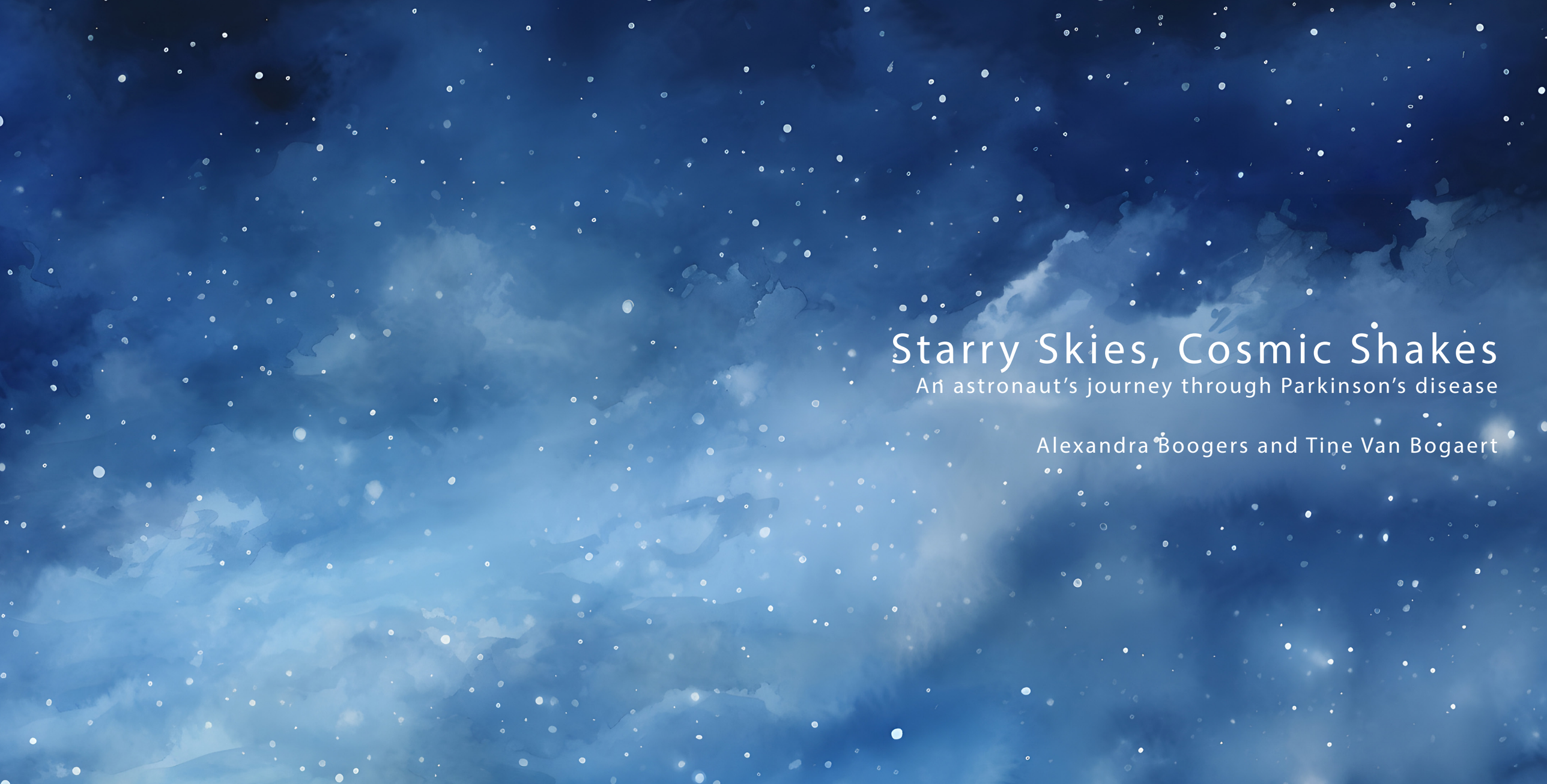
Alexandra Boogers and Tine Van Bogaert

Starry Skies, Cosmic Shakes is the story about an astronaut, called Alex, who gets diagnosed with Parkinson's disease. Alex learns about their symptoms which improve with medication and deep brain stimulation.

The authors' vision for the book is to serve as a conversation starter between (grand)parents who were diagnosed with Parkinson's disease and their (grand)children.

'Why does it say dopamine on the bottle?' Alex asked. 'Dopamine is a substance in the brain. People with Parkinson's have less dopamine,' replied Dr. Twitchy.





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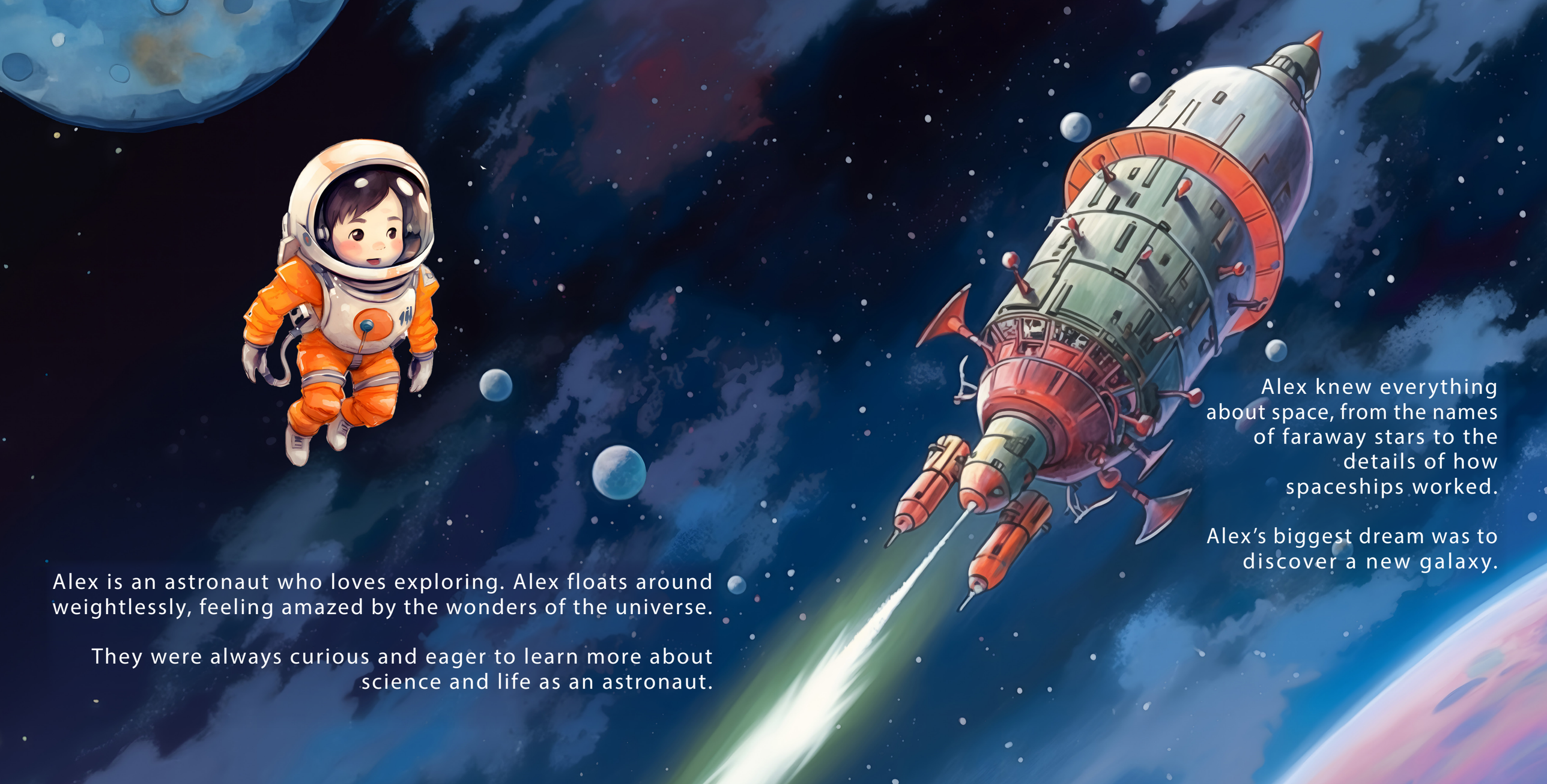
To you, the one who that makes the difference

Foreword

Starry Skies, Cosmic Shakes was written with a few different objectives. Firstly, the diagnosis of Parkinson's disease can be quite impactful for the individual who is receiving the diagnosis but also for their family. We wrote this book as a tool for people with Parkinson's disease to discuss the disorder and its treatment with their children or grandchildren. Secondly, this book serves a fundraising purpose meaning that the profits will be used to support research that focuses on improving quality of life in the Parkinson's community.

The illustrations of the book were generated using artificial intelligence though many (human) edits were necessary to integrate the different images into one illustration per page, keeping consistency in style across the entire story. With this book, we want to celebrate the possibilities that AI brings while acknowledging the major human input that is required to obtain high-quality output. Moreover, we hope that Alex's adventure sparks children's interest in science and technology as our future will heavily rely on people skilled in science, technology, engineering and mathematics.

We hope you enjoy the read!

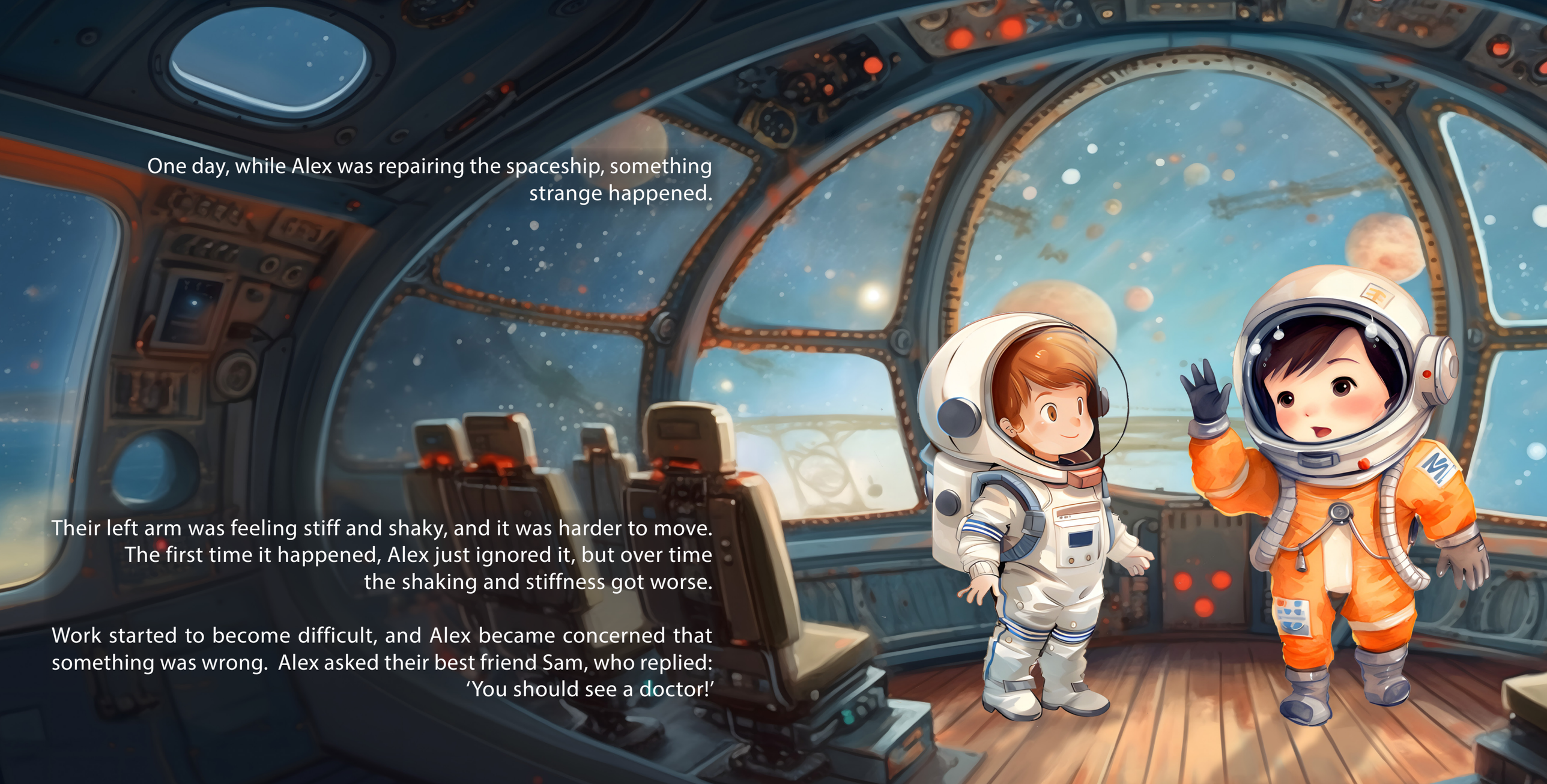


Alex is an astronaut who loves exploring. Alex floats around weightlessly, feeling amazed by the wonders of the universe.

They were always curious and eager to learn more about science and life as an astronaut.

Alex knew everything about space, from the names of faraway stars to the details of how spaceships worked.

Alex's biggest dream was to discover a new galaxy.



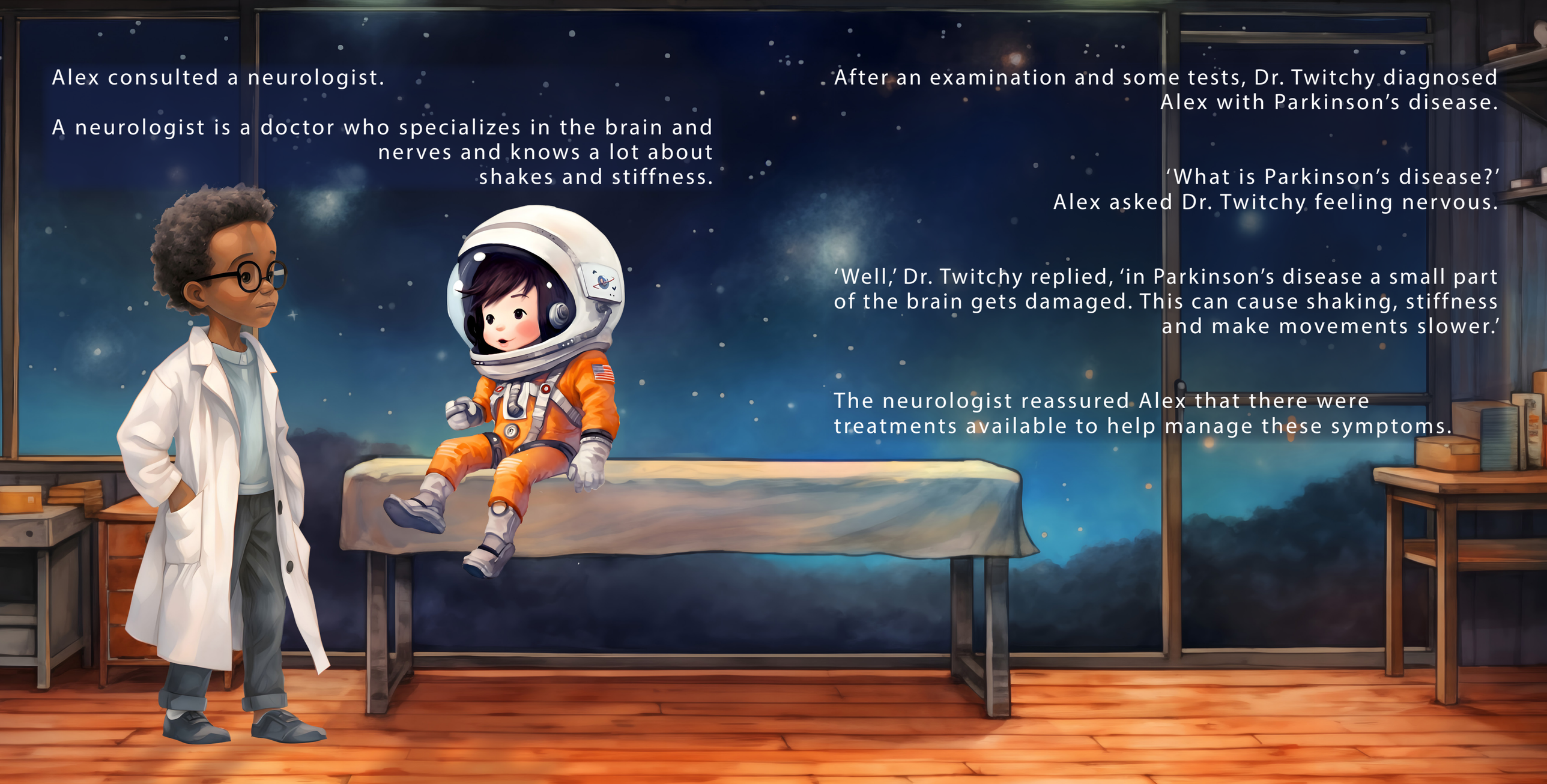
One day, while Alex was repairing the spaceship, something strange happened.

Their left arm was feeling stiff and shaky, and it was harder to move. The first time it happened, Alex just ignored it, but over time the shaking and stiffness got worse.

Work started to become difficult, and Alex became concerned that something was wrong. Alex asked their best friend Sam, who replied: 'You should see a doctor!'

Alex consulted a neurologist.

A neurologist is a doctor who specializes in the brain and nerves and knows a lot about shakes and stiffness.

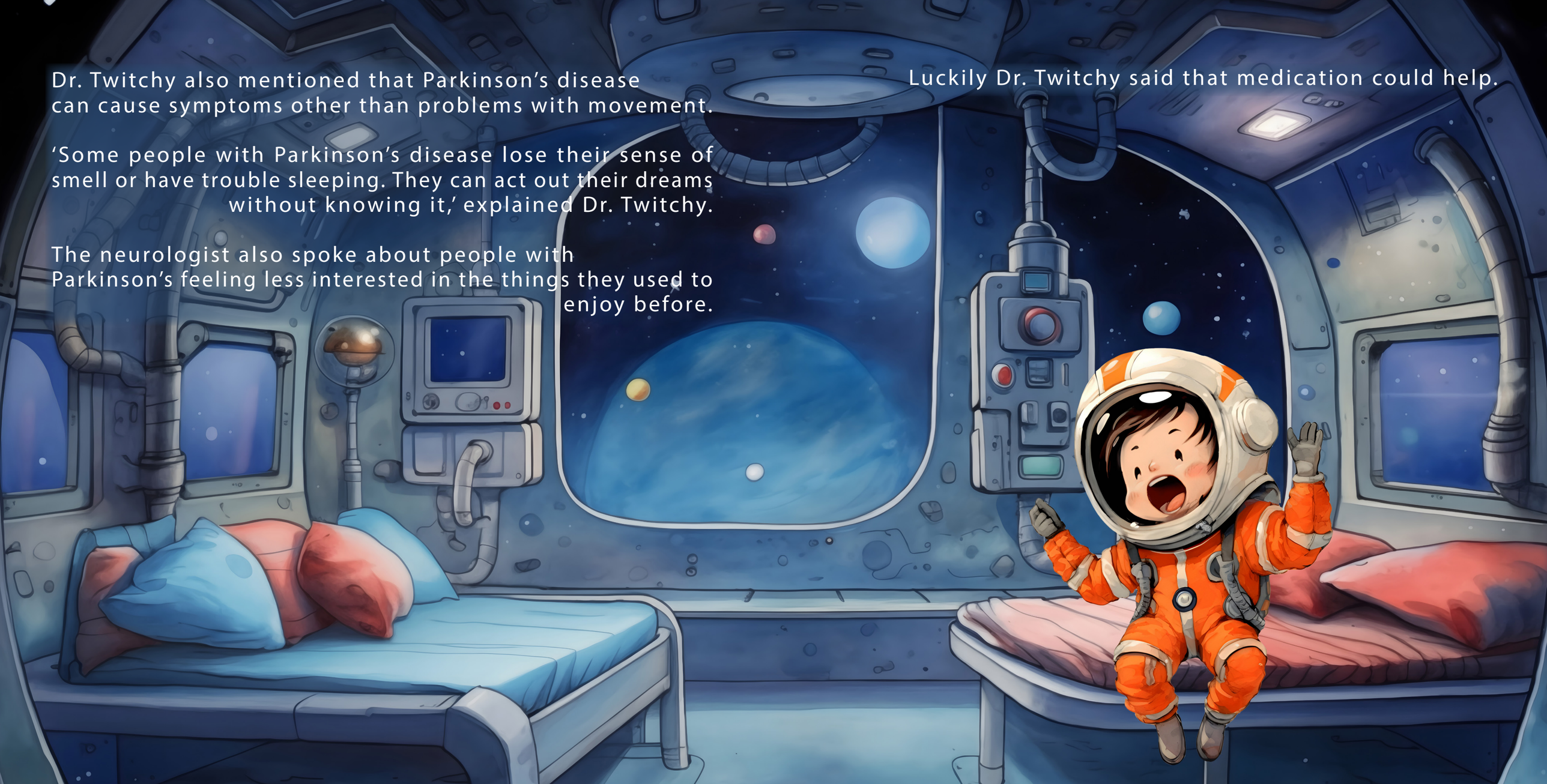


After an examination and some tests, Dr. Twitchy diagnosed Alex with Parkinson's disease.

'What is Parkinson's disease?' Alex asked Dr. Twitchy feeling nervous.

'Well,' Dr. Twitchy replied, 'in Parkinson's disease a small part of the brain gets damaged. This can cause shaking, stiffness and make movements slower.'

The neurologist reassured Alex that there were treatments available to help manage these symptoms.

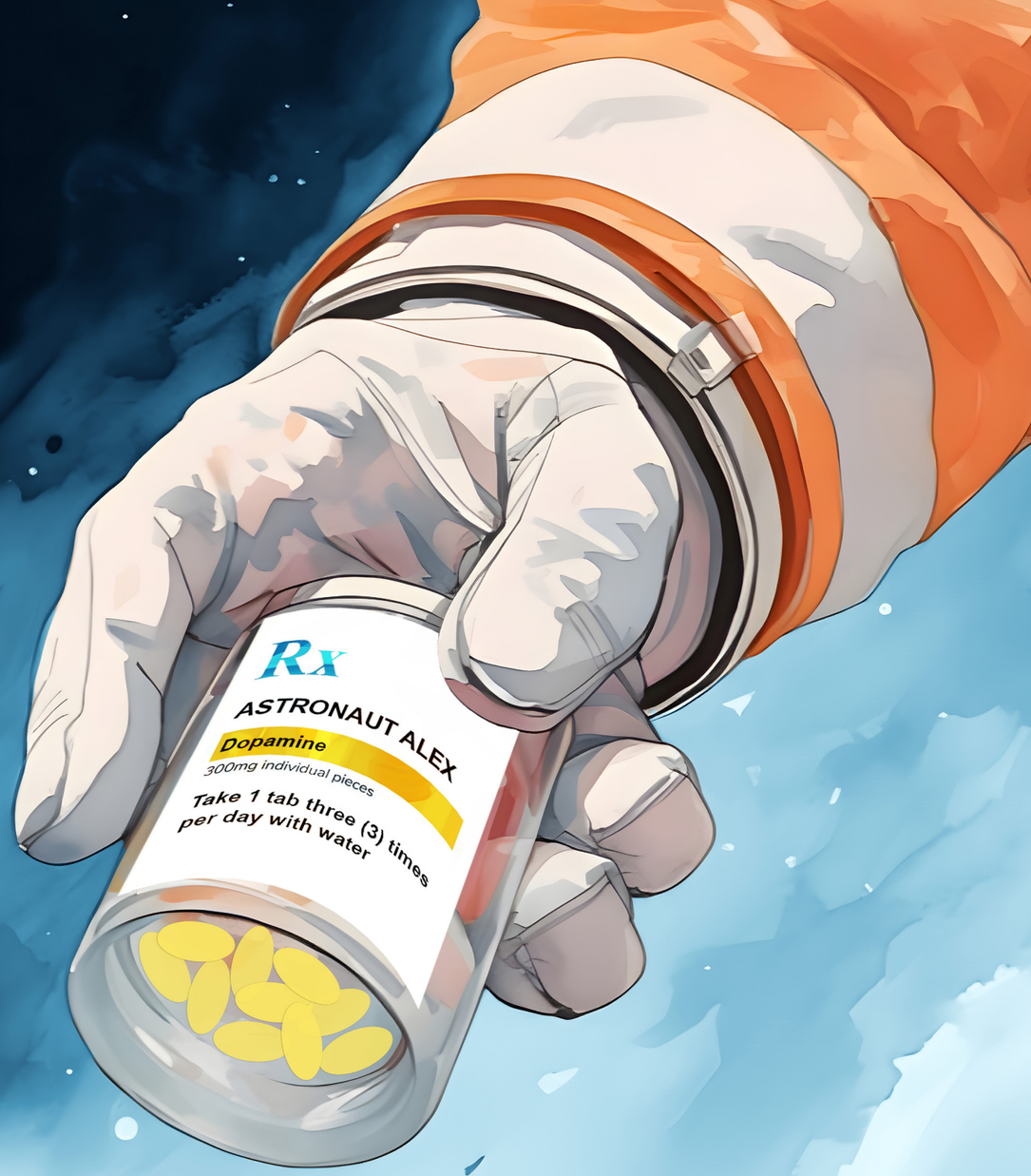

Dr. Twitchy also mentioned that Parkinson's disease can cause symptoms other than problems with movement.
'Some people with Parkinson's disease lose their sense of smell or have trouble sleeping. They can act out their dreams without knowing it,' explained Dr. Twitchy.
The neurologist also spoke about people with Parkinson's feeling less interested in the things they used to enjoy before.
Luckily Dr. Twitchy said that medication could help.

Alex was given tablets to manage their symptoms. ‘Why does it say dopamine on the bottle?’ Alex asked.

‘Dopamine is a substance in the brain. People with Parkinson’s have less dopamine. That is why you have to take these pills,’ said Dr. Twitchy.

The tablets were able to make the shaking disappear and allow Alex to move their arms and legs more smoothly. Alex was thrilled to be able to draw space maps and dance in zero gravity again.

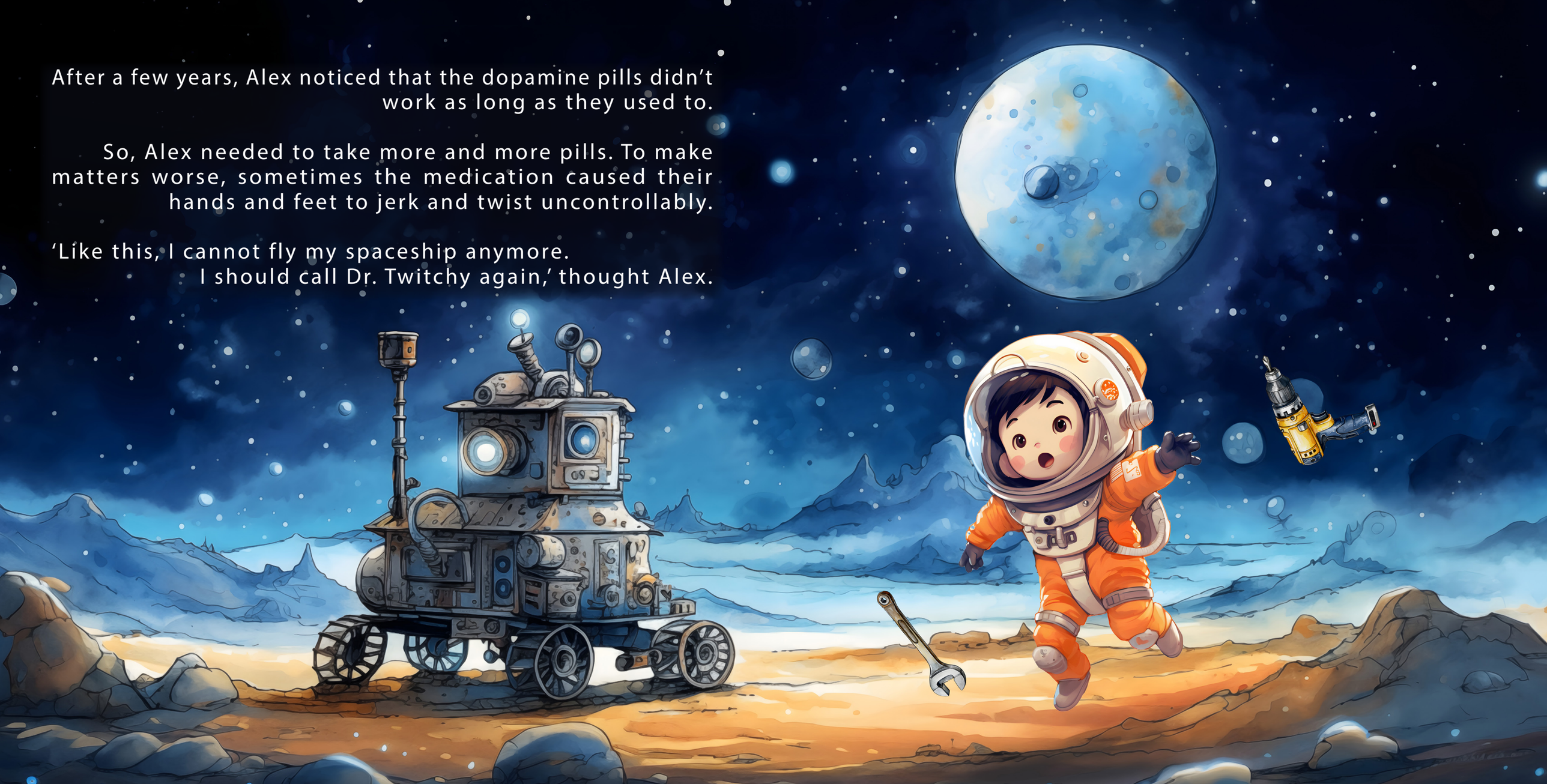
The dopamine pills gave Alex a new burst of energy.

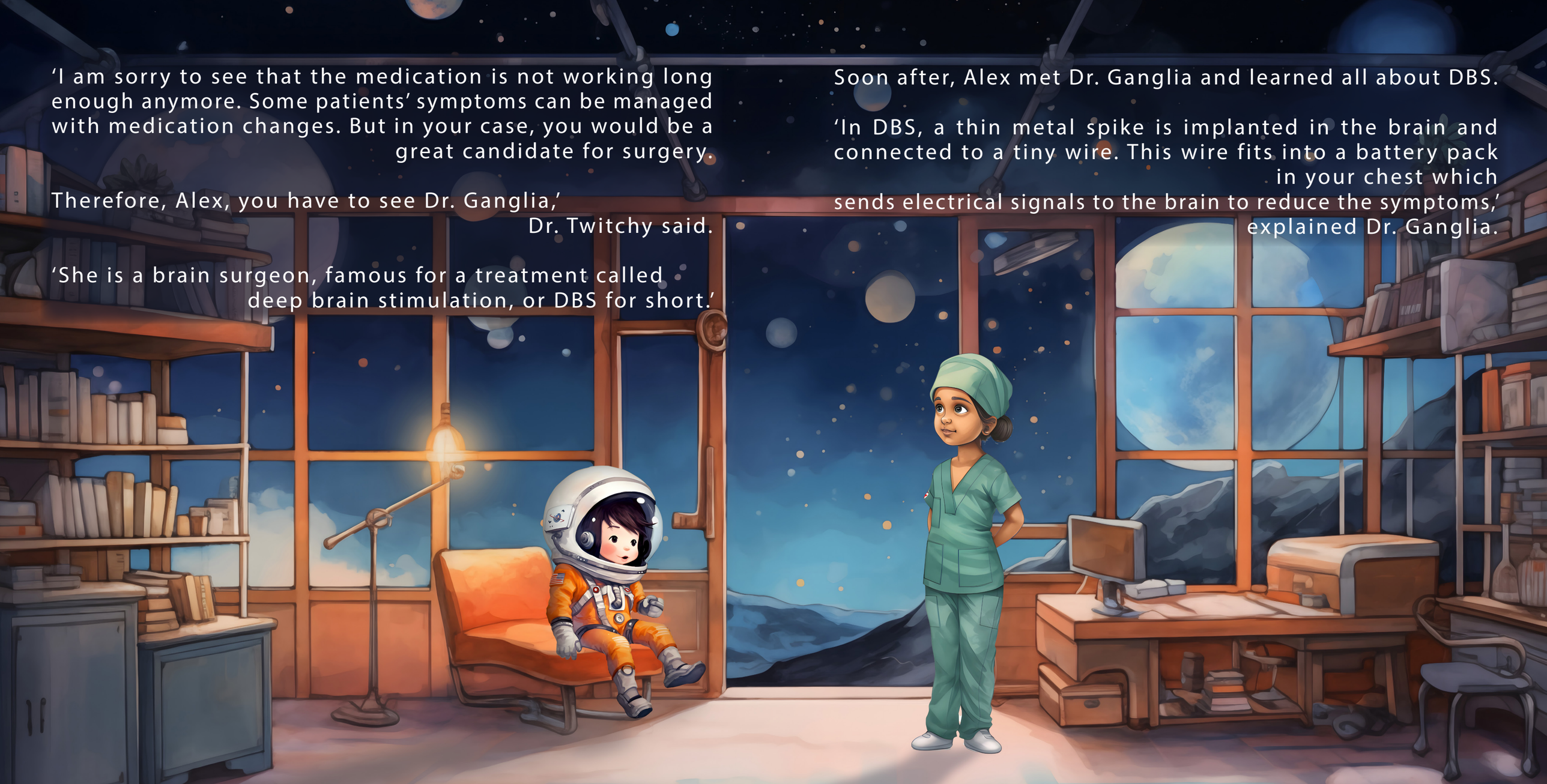


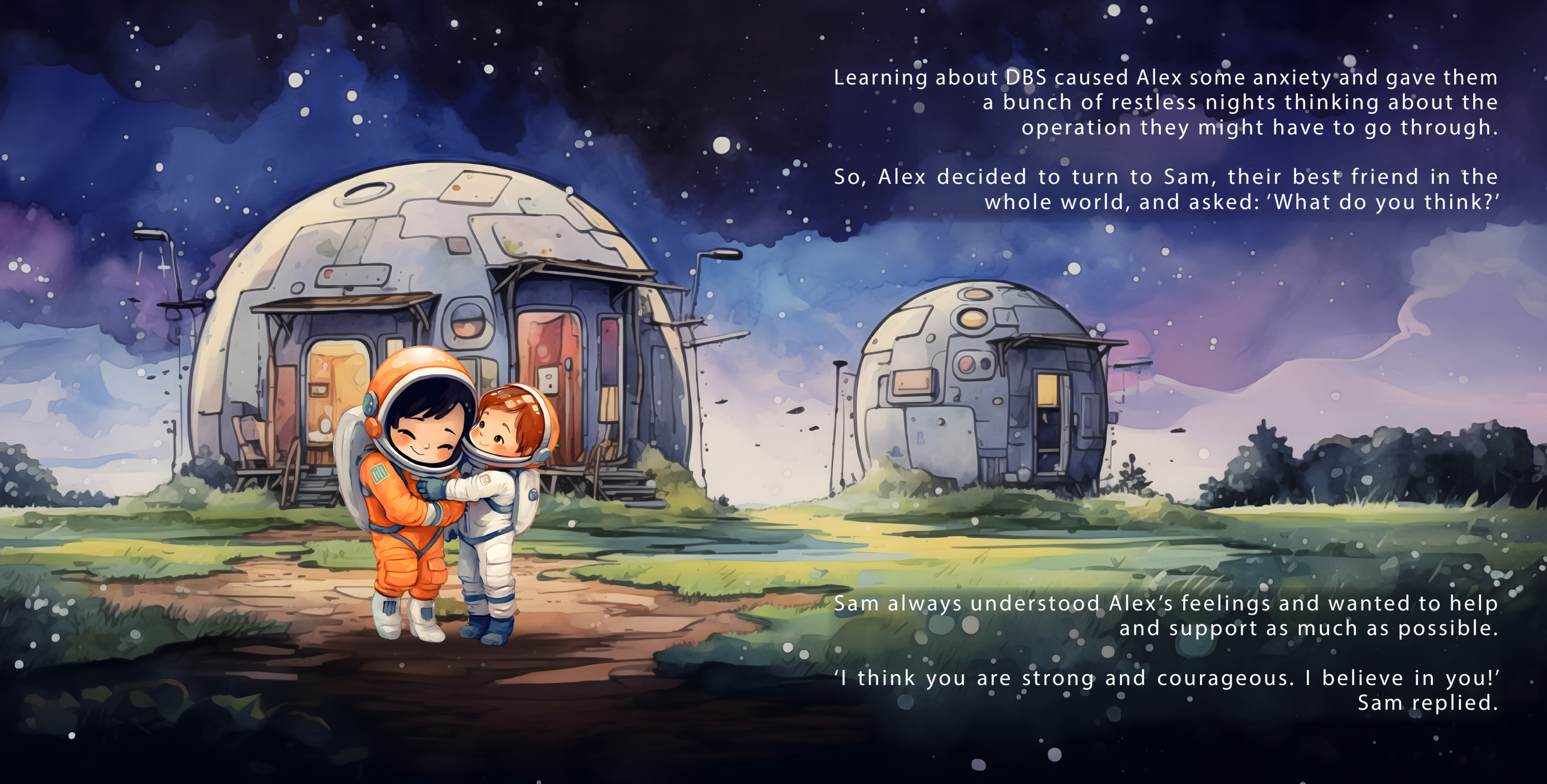
After a few years, Alex noticed that the dopamine pills didn't work as long as they used to.

So, Alex needed to take more and more pills. To make matters worse, sometimes the medication caused their hands and feet to jerk and twist uncontrollably.

'Like this, I cannot fly my spaceship anymore.
I should call Dr. Twitchy again,' thought Alex.




‘I am sorry to see that the medication is not working long enough anymore. Some patients’ symptoms can be managed with medication changes. But in your case, you would be a great candidate for surgery.
Therefore, Alex, you have to see Dr. Ganglia,’ Dr. Twitchy said.
‘She is a brain surgeon, famous for a treatment called deep brain stimulation, or DBS for short.’
Soon after, Alex met Dr. Ganglia and learned all about DBS.
‘In DBS, a thin metal spike is implanted in the brain and connected to a tiny wire. This wire fits into a battery pack in your chest which sends electrical signals to the brain to reduce the symptoms,’ explained Dr. Ganglia.

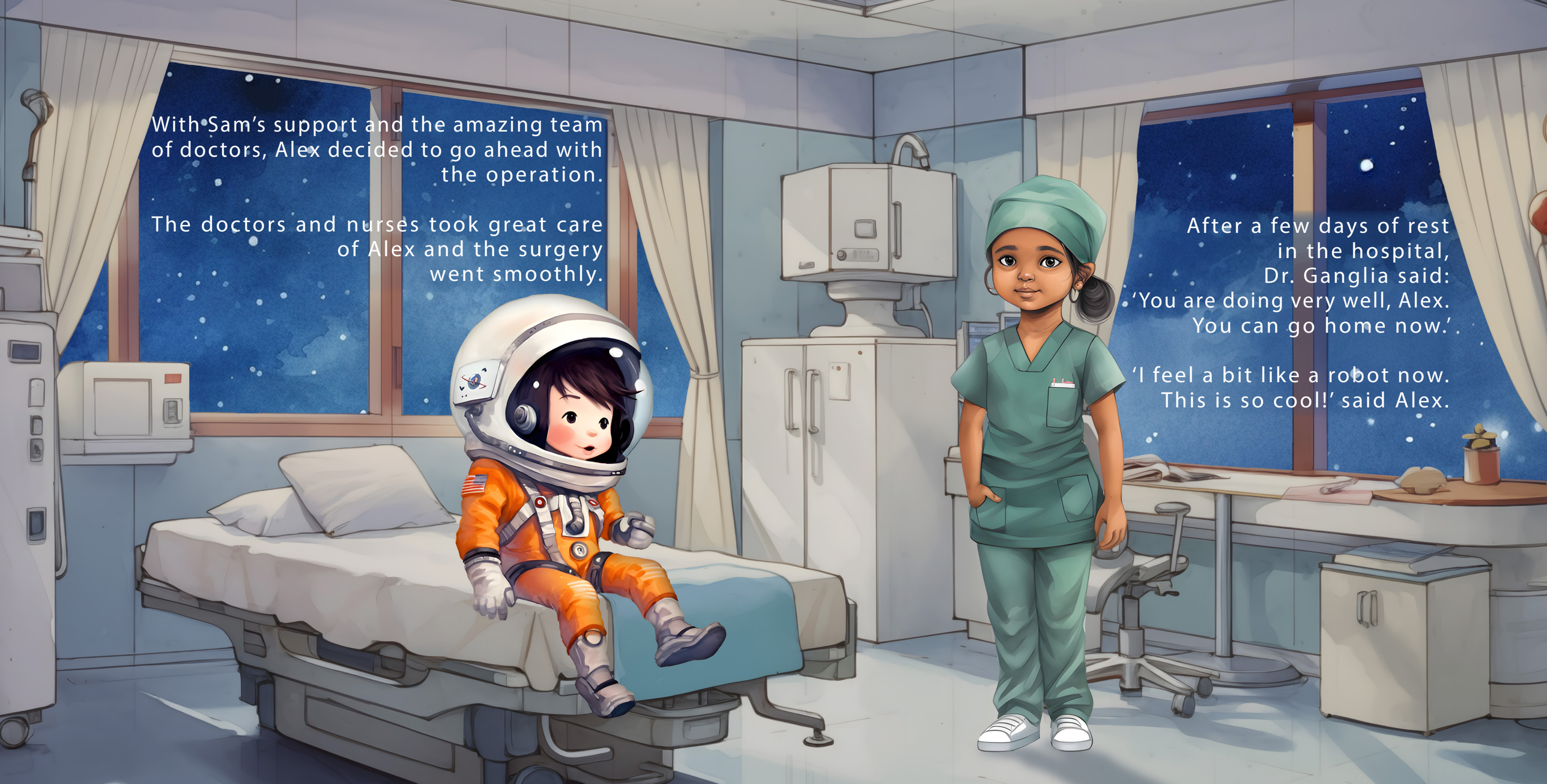


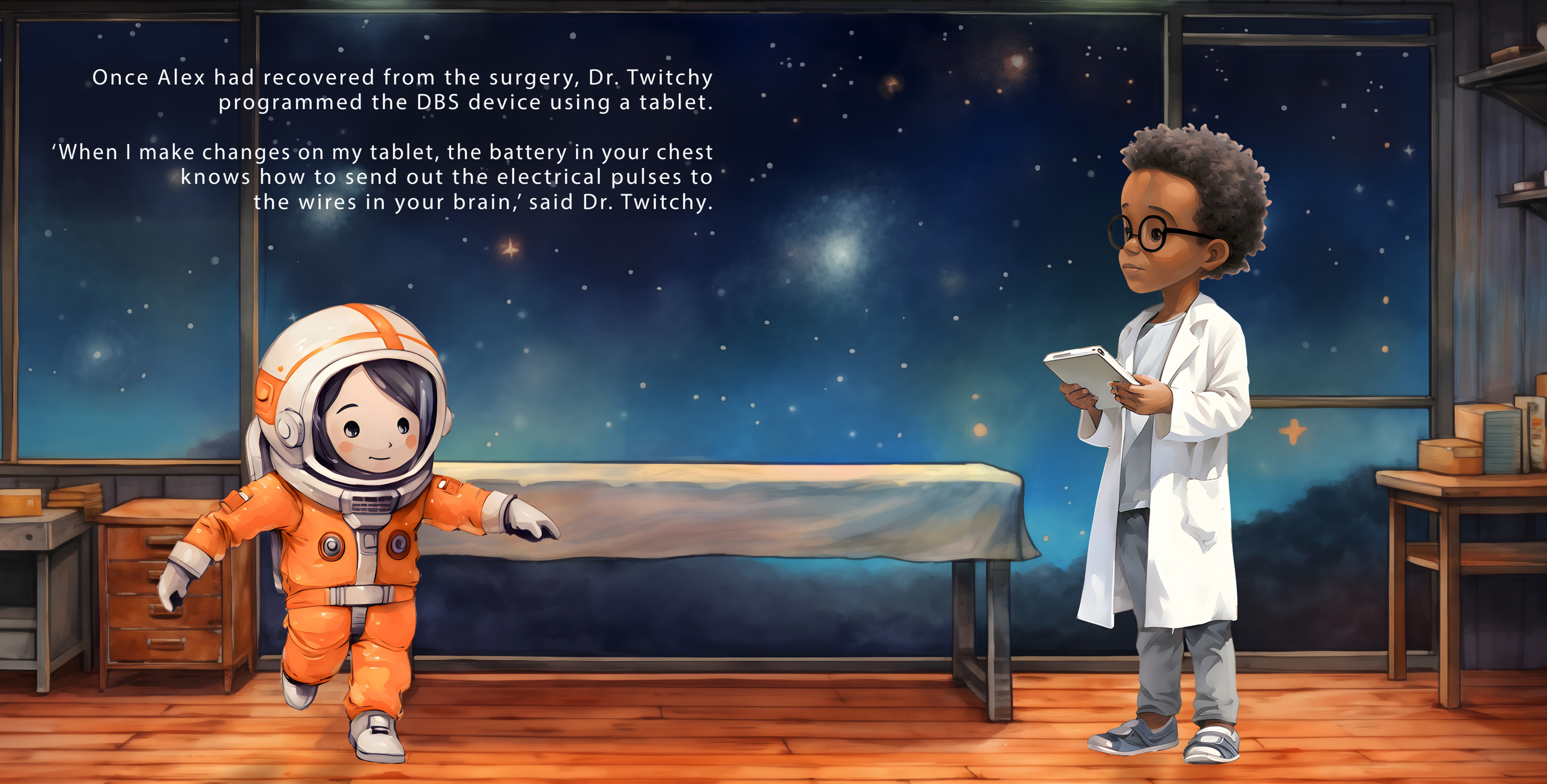
Learning about DBS caused Alex some anxiety and gave them a bunch of restless nights thinking about the operation they might have to go through.

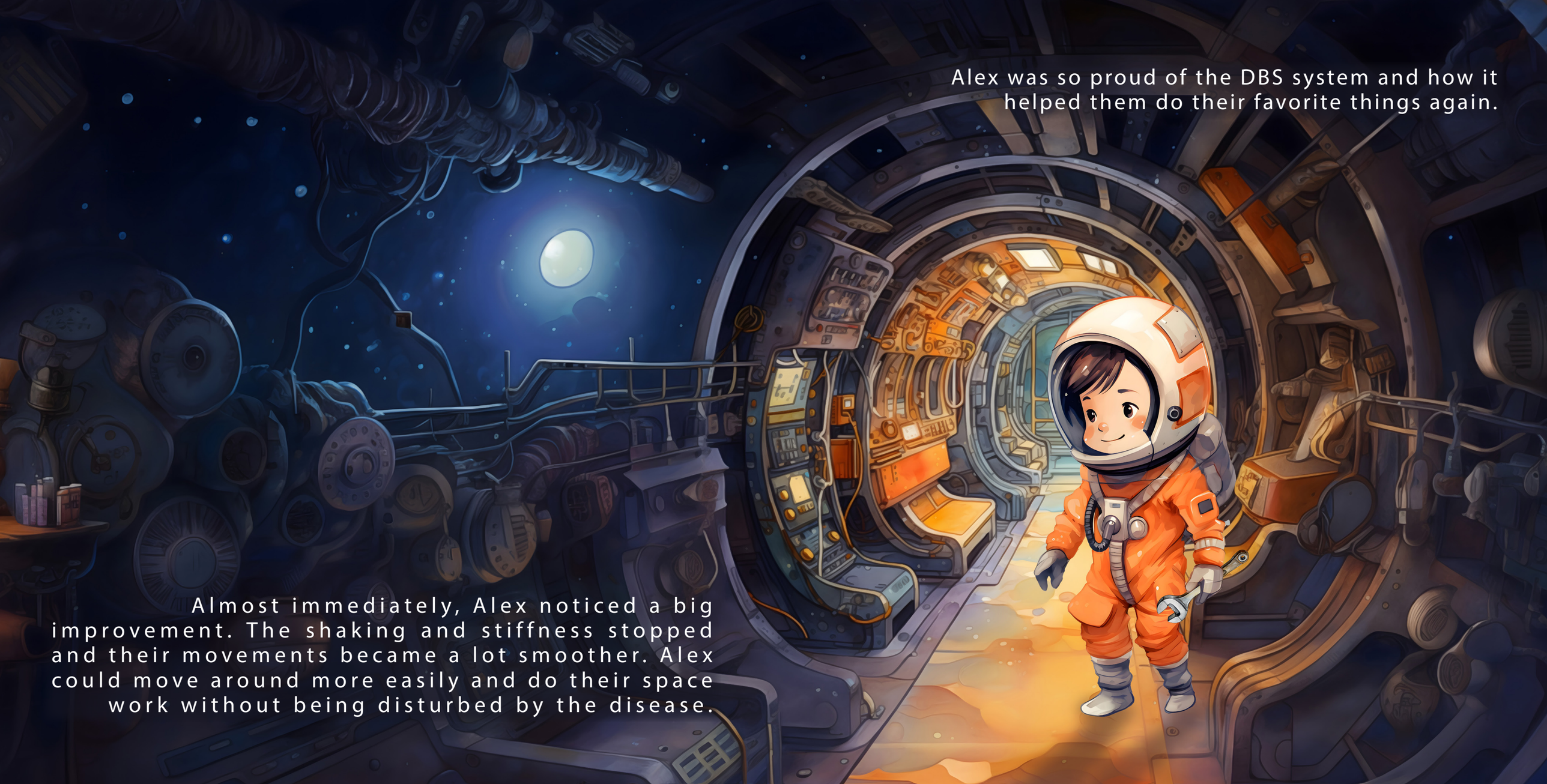
So, Alex decided to turn to Sam, their best friend in the whole world, and asked: ‘What do you think?’

Sam always understood Alex’s feelings and wanted to help and support as much as possible.

‘I think you are strong and courageous. I believe in you!’ Sam replied.


With Sam's support and the amazing team of doctors, Alex decided to go ahead with the operation.
The doctors and nurses took great care of Alex and the surgery went smoothly.
After a few days of rest in the hospital, Dr. Ganglia said: 'You are doing very well, Alex. You can go home now.'
'I feel a bit like a robot now. This is so cool!' said Alex.


Once Alex had recovered from the surgery, Dr. Twitchy programmed the DBS device using a tablet.
'When I make changes on my tablet, the battery in your chest knows how to send out the electrical pulses to the wires in your brain,' said Dr. Twitchy.

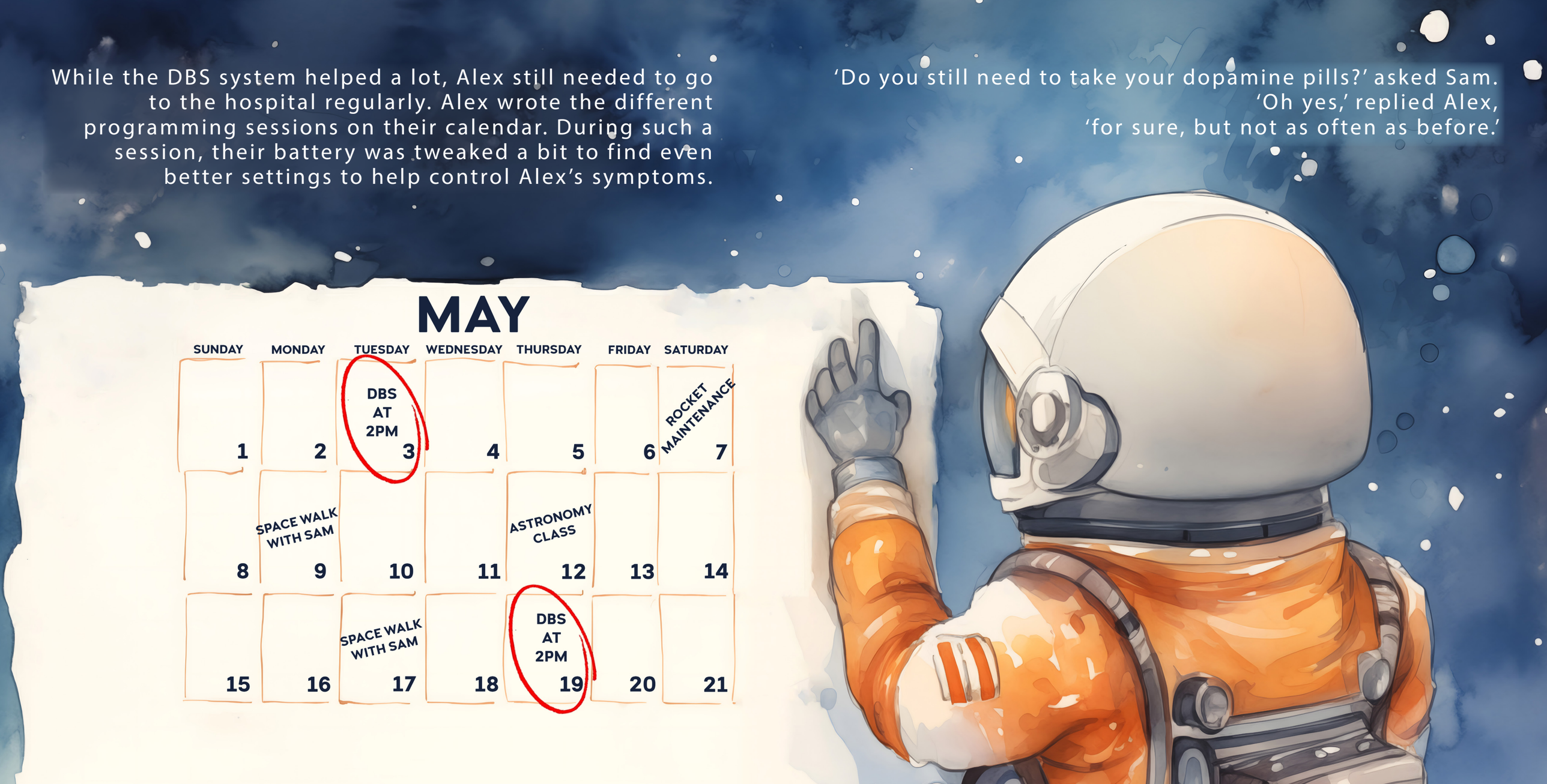


Alex was so proud of the DBS system and how it helped them do their favorite things again.

Almost immediately, Alex noticed a big improvement. The shaking and stiffness stopped and their movements became a lot smoother. Alex could move around more easily and do their space work without being disturbed by the disease.

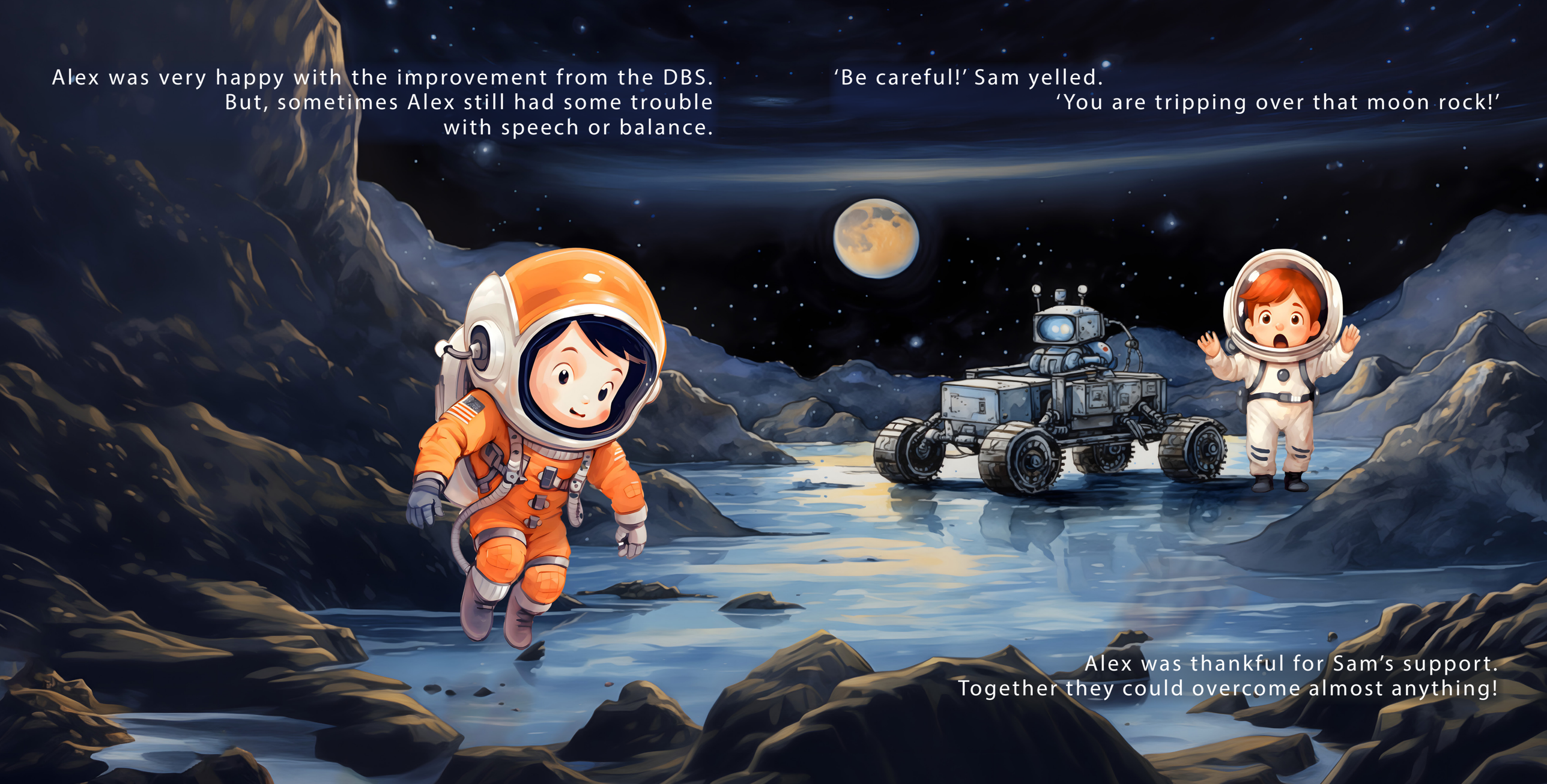
While the DBS system helped a lot, Alex still needed to go to the hospital regularly. Alex wrote the different programming sessions on their calendar. During such a session, their battery was tweaked a bit to find even better settings to help control Alex's symptoms.

'Do you still need to take your dopamine pills?' asked Sam.
'Oh yes,' replied Alex,
'for sure, but not as often as before.'

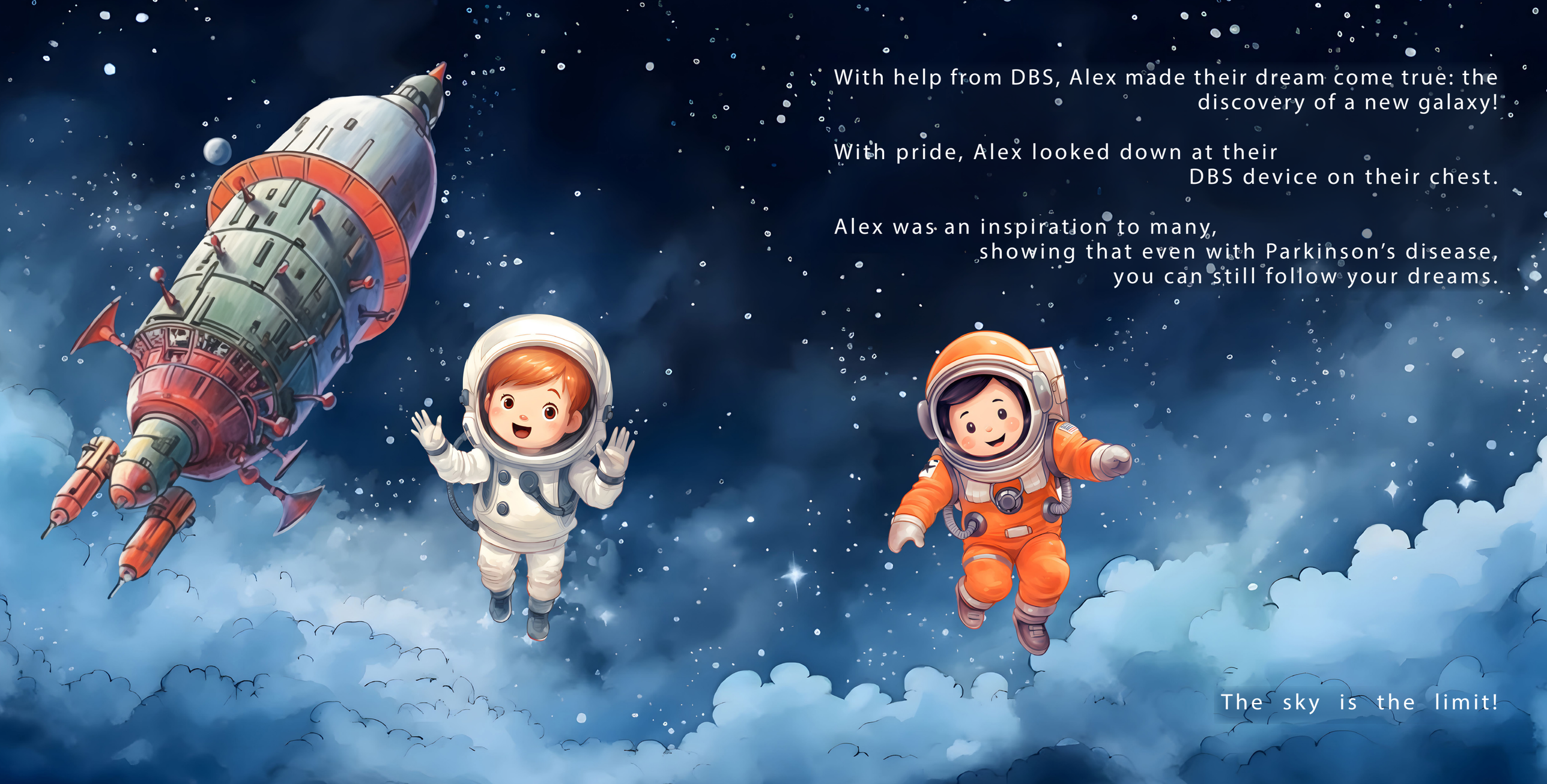


Alex was very happy with the improvement from the DBS.
But, sometimes Alex still had some trouble
with speech or balance.

‘Be careful!’ Sam yelled.
‘You are tripping over that moon rock!’



Alex was thankful for Sam’s support.
Together they could overcome almost anything!



With help from DBS, Alex made their dream come true: the discovery of a new galaxy!

With pride, Alex looked down at their DBS device on their chest.

Alex was an inspiration to many, showing that even with Parkinson's disease, you can still follow your dreams.

The sky is the limit!

Alexandra Boogers graduated as a neurologist at the University of Antwerp, Belgium. She obtained her PhD on the topic of deep brain stimulation at the Catholic University of Leuven, Belgium. Currently, she is a clinical and post-doctoral fellow at Toronto Western Hospital in Canada.

Tine Van Bogaert is a human health engineer and currently working as a neuroscientist and PhD candidate at the Catholic University of Leuven, Belgium. Her research topic is the effect of deep brain stimulation on brain waves of deep brain structures.

We would like to acknowledge several people who were involved in the realization of this project. First and foremost, the people living with Parkinson's disease and their families. They are a continuous source of inspiration to work harder and find better treatment options for this disease and hopefully at some point in the not too distant future, a cure.

Thank you to all patients who advocate for patient education and raising awareness about Parkinson's disease and its treatments. We hope that this book can serve as a medium for this cause. A special thank you goes to Ann Bada-Crema, whose husband lived with Parkinson's disease and experienced DBS surgery, for helping with the editing and formatting of the artwork, together with her team. Thank you to Benjamin Stecher who did an amazing job editing the text but also for bringing his personal experience as a person with Parkinson's to the table.

Thank you to all our mentors, neurologists, neurosurgeons and neuroscientists, who we collaborated with over the years. They taught us all about Parkinson's disease and deep brain stimulation but also showed us the importance of genuinely listening to patients and spending ample time explaining the diagnosis, the treatment options and managing patient expectations so diligently.

A special thank you to Françoise Chombar who has been a trailblazer for women in science, constantly raising awareness of having more young people, especially girls, involved in Science, Technology, Education and Mathematics. You were one of the sources of inspiration in writing this book.

Lastly, thank you to our families for their unconditional love and support.