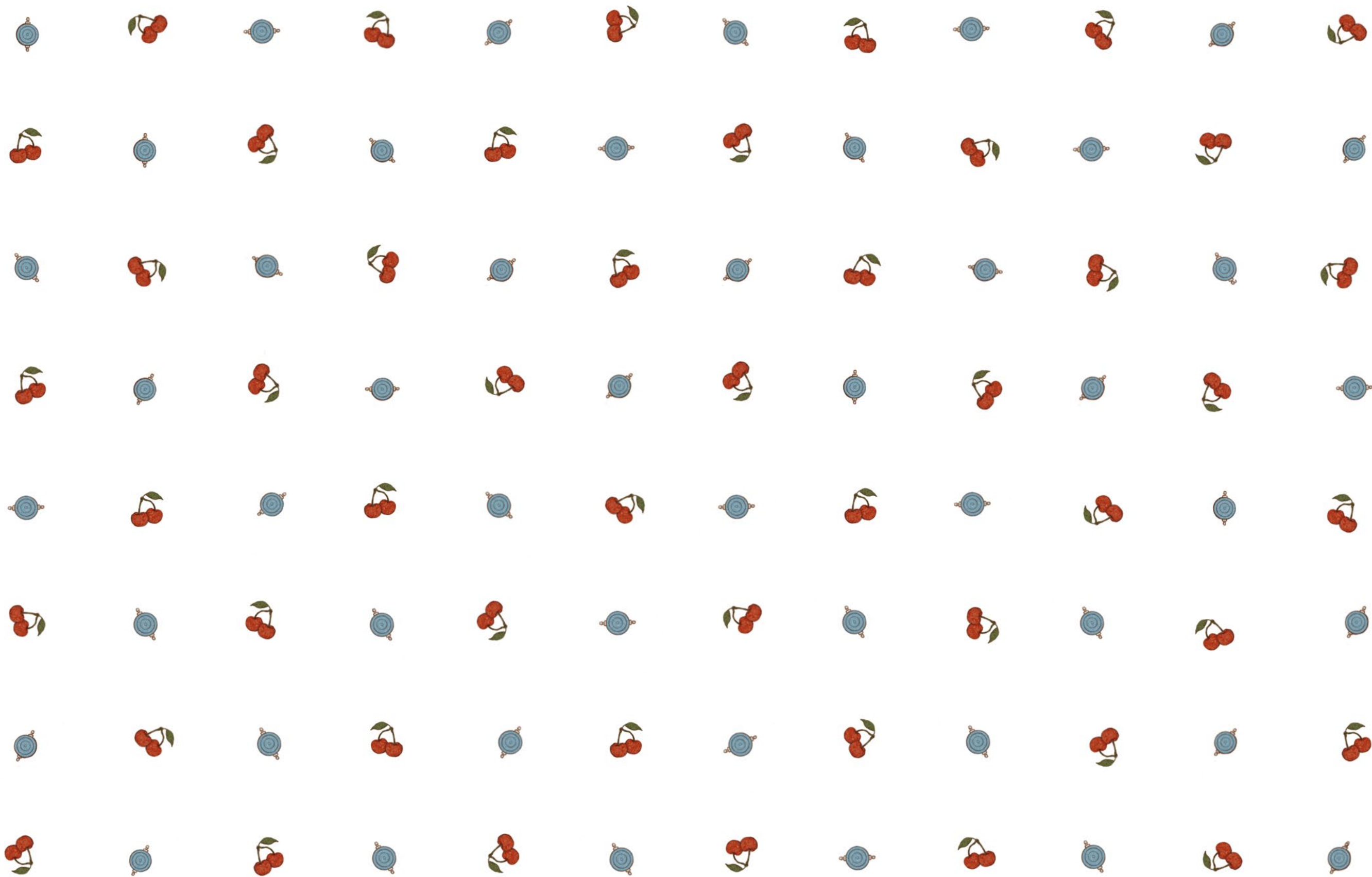
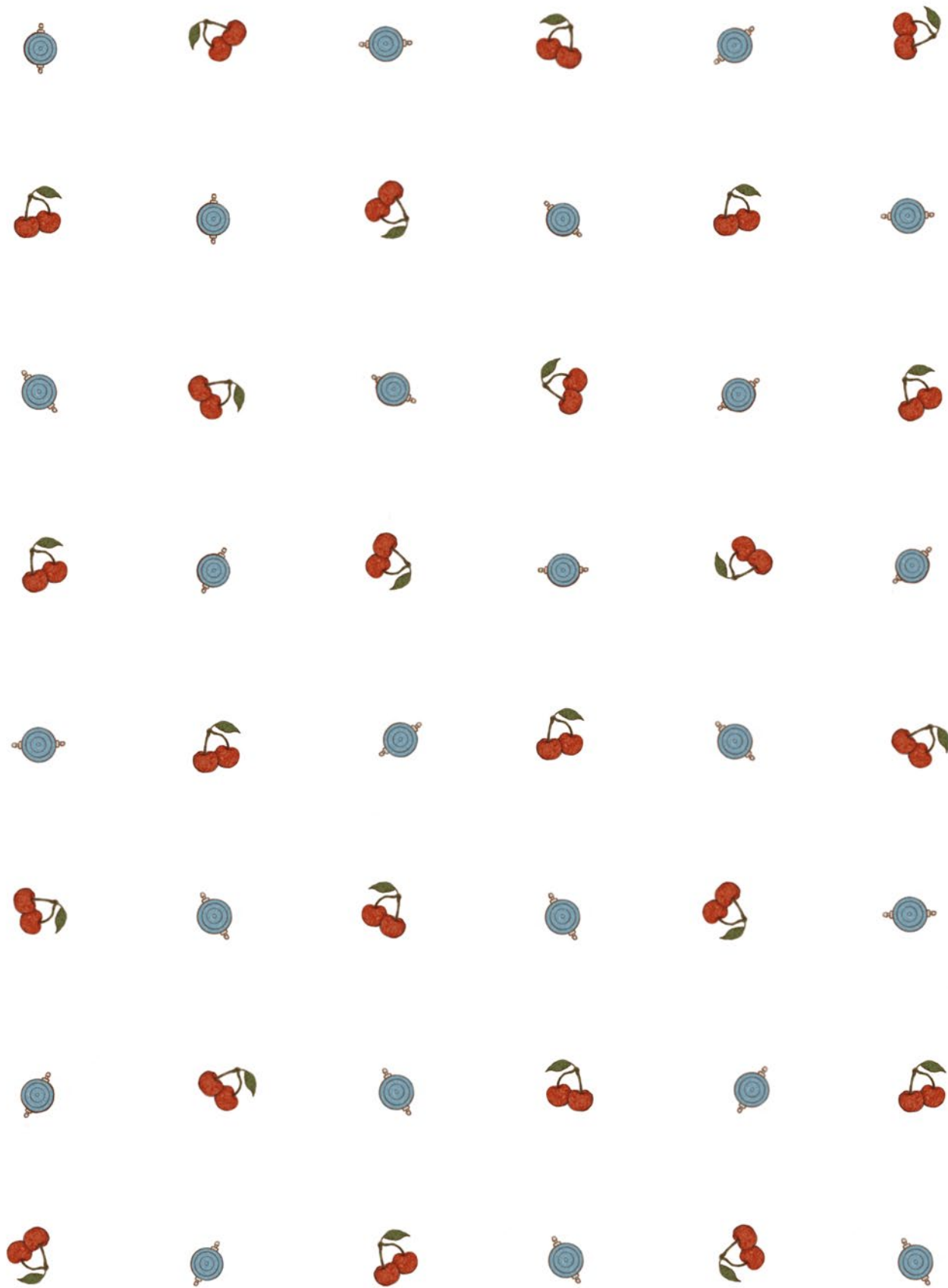




KARL'S GUARD





KARL'S GUARD



A STORY BY MIETHKE
WITH ILLUSTRATIONS BY
MINGLIANG SUN



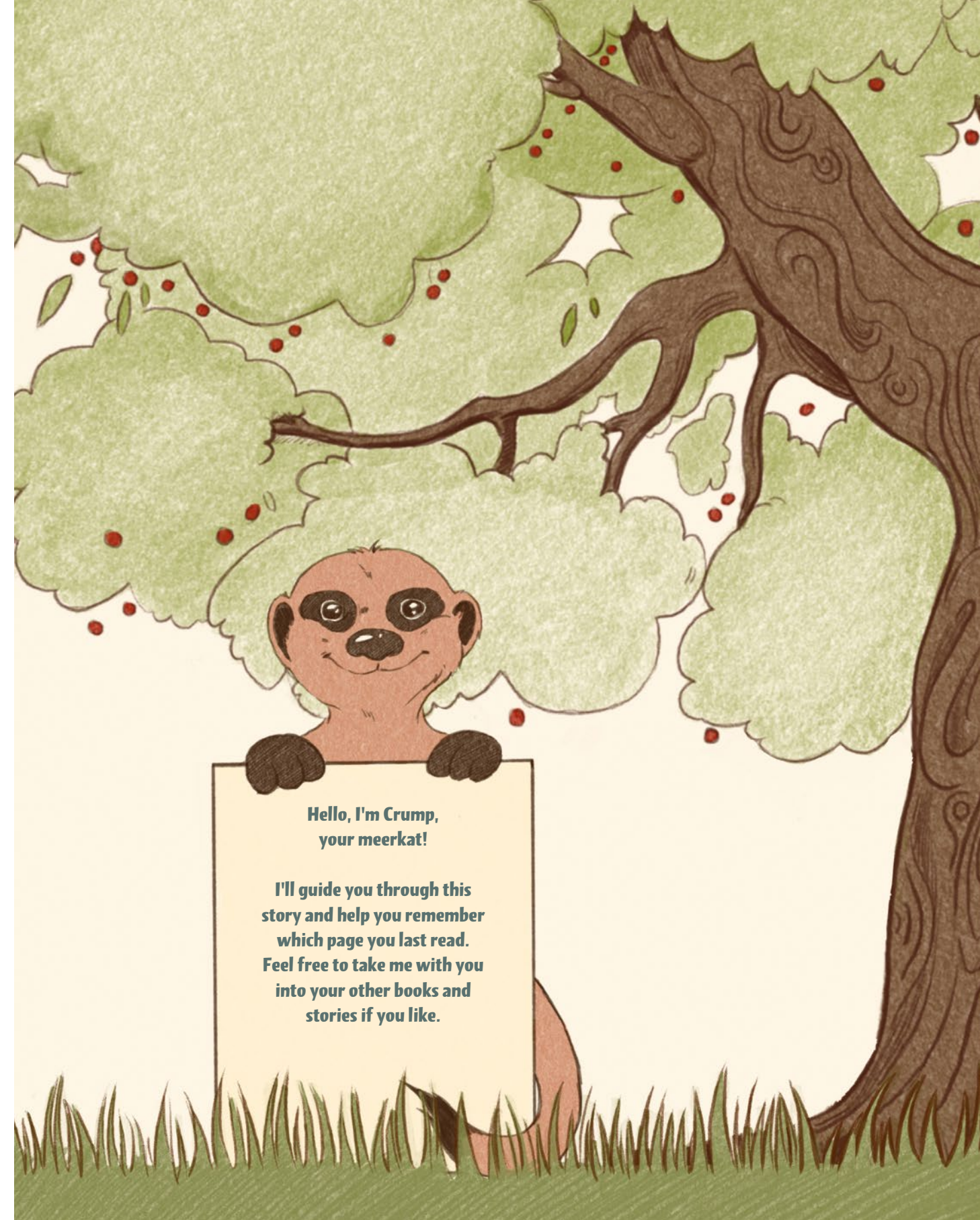
FOREWORD

PD Dr. med. Ulrich-W. Thomale

When water builds up in the head, this is known as hydrocephalus which can be corrected by surgery. Of all the operations performed on the brain, hydrocephalus surgery has historically been the most successful in brain surgery. While many of these patients had to die or were severely disabled before 1950, the aim of treatment today is to enable children to develop as normally as possible. However, hydrocephalus is not actually a disease, rather is always caused by a pre-existing problem. Specialists in the treatment of hydrocephalus can now treat the clinical picture so well that the development of the children depends little on the hydrocephalus but rather on this underlying disease.

The operation usually involves draining the cerebrospinal fluid into another body cavity, usually the abdominal cavity. The drainage is called a "shunt" and includes, among other things, a valve to control the amount of cerebrospinal fluid drainage. Only through very close and continuous collaboration between various doctors and engineers has it been possible to design the valves and shunt materials so well today that they cause few problems and already approach very closely to normal cerebrospinal fluid drainage. As humans produce around half a liter of cerebrospinal fluid per day, the shunt must function well in patients every minute, every hour, every day and every year. As a child grows over the years until adulthood, it is highly likely that at least one further operation will be necessary to maintain the shunt system. This is something the parents and child need to be prepared for and it is necessary to prevent shunt malfunction which can lead to nerve water pressure damaging the brain. All those affected must always remember that it is not the shunt that makes a child a patient, rather that it provides the conditions for a child to develop as normally as possible.

Patients with well-treated hydrocephalus and an underlying disease that has not caused any further damage as such generally cope well with a shunt in everyday life. Nevertheless, stressful situations can lead to headaches, concentration problems or other limitations, which also represent a slight disability. However, you cannot see hydrocephalus or a shunt on a person's face. Therefore, it can sometimes be difficult for those affected to receive appropriate consideration from their environment due to their illness. Thus, education and sharing experiences about the clinical picture are of great importance in order to be able to provide those affected with the necessary support and compassion. Every illness is not just the illness of the other person, but is always also the one that could affect you next. So, dealing with the person affected is always also dealing with ourselves.



THREE FRIENDS

It's summer. Merle, Anton and Karl are cheering on the wheelchair basketball players from Karl's favorite team, who have just scored a great basket. Karl also needs a wheelchair. He loves this sport and plays it himself in his free time.

Merle and Anton sometimes come along and watch or take the opportunity to practice hitting the basket. They are always amazed at Karl's skill with the wheelchair and the ball.



ANTON EXPLAINS

WHY DOES KARL NEED A WHEELCHAIR?

Karl has a disease called spina bifida, which means that the spine and spinal cord in his mother's womb have not developed in the same way as in healthy children. Around one in 3,000 children are born with this condition and in about half of these children the spine is so curved that it can lead to paralysis of the legs or other disorders - such as hydrocephalus. As with Karl.



ANTON EXPLAINS

WHAT IS HYDROCEPHALUS?

Hydrocephalus is a Greek word made up of the words "hydro" = water and "cephale" = head. All people have cerebrospinal fluid, which is important for many functions, inside their head. People with hydrocephalus have too much cerebrospinal fluid in their head and this causes a lot of pressure and problems inside the head. To drain the excess cerebrospinal fluid, shunts (I will explain this word in more detail later) are usually implanted and these act like guards to ensure that the intracranial pressure is as normal as possible.



Merle and Anton have known Karl for over a year now. They met him at a hospital when Merle suddenly had to have an operation for her hydrocephalus. Since then, the three of them have been best friends and often lie together under the cherry tree in Merle's garden and tell each other stories of imaginary adventures.



Today is a very special day for Karl: he has been waiting for this basketball game for so long and now it looks like his favorite team is going to win. Anton is happy with Karl and wants to hug his friend. He accidentally bumps his arm, which was in a cast, against his shoulder. Karl protests loudly and Merle laughs at her two friends.



Anton is also glad that he was able to go to the game with his friends. It almost didn't work out. He fell from the cherry tree in Merle's garden two weeks ago and broke his left arm. That alone would only be half as bad. But when he fell down, he hit his head somewhere - so hard that he got a concussion.



Anton was in hospital for a week with a headache and this time seemed like an eternity to him. He was constantly nauseous, dizzy and very bored because he couldn't even watch TV or read due to the concussion. So, he thought about it. For a long time and a lot. Not a difficult exercise for Anton, who always wants to understand everything exactly.

Here in the hospital and with these terrible headaches, he has thought mainly about Merle and Karl, who both have hydrocephalus.



He had seen how badly Merle was doing a year ago. But only now has he understood how much headaches can make your day difficult. Anton always notices that Karl suddenly becomes calmer when he has a headache. Karl would never complain. Karl and Merle are very similar in that respect. But Karl doesn't always feel as well as Merle. Now - here in hospital - it has become very clear to Anton what Karl has to go through every time and his admiration for his older friend's strength and fortitude has grown even greater. Anton is already amazed at Merle's and Karl's courage and effortlessness. They come by every day and bring along good humor to the hospital. Anton is always waiting for them and because he wants to go to the basketball game with Merle and Karl in a week's time, he sticks to the most important rule for the rest of the day:



rest, rest and more rest... Boring! But helpful, because today the time has finally come: Anton is allowed to leave the hospital. Happy and content, the three of them go home and look forward to an afternoon together in Merle's garden.

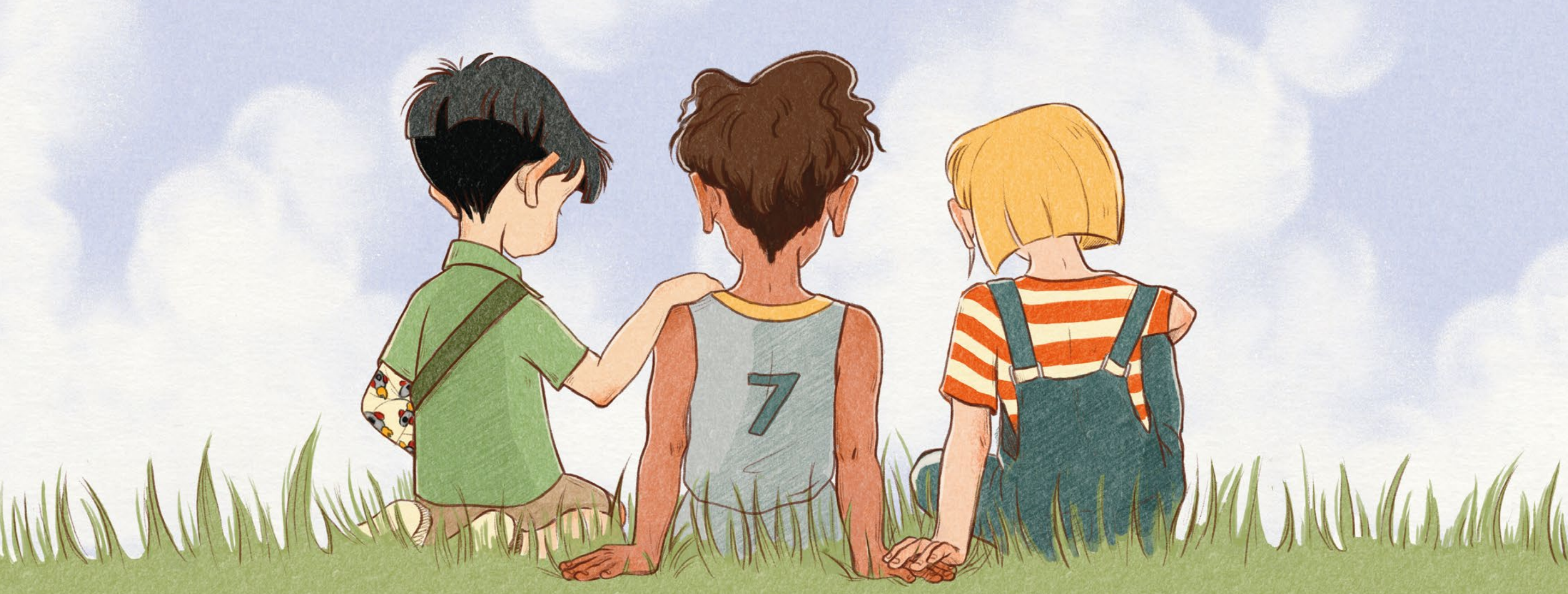


KARL'S VALVE

Vacation is about to start and the three of them make plans under the cherry tree later that day. Traveling would be great. They would love to go to a summer camp together. Preferably far away. But that's not as easy as it sounds. Karl hasn't been feeling well for some time now. Anton knows his friend well and has noticed this for a while now. Merle has too, but like Karl, she tries not to think about it. Karl's mother can't be persuaded to let Karl go away without his parents.



Anton thinks about the headache he had a week ago and now wants to know more: "Tell me, Karl, what's wrong with you?" "Nothing at all. I'm fine," Karl gets defensive. He doesn't want to talk about it. But Anton won't be shaken off. "I can see it. You're not well. You canceled three times last week. There's not that much homework before the vacation. So, what's going on? We're your friends." Now Merle listens and looks questioningly at Karl. It's time to talk about it. Even Karl realizes that now.



"No idea. Constant headaches. My hydrocephalus guard isn't doing a good job right now." Karl grumbles to himself. Still a little defensive, but actually rather sad, at a loss. Merle and Anton look at each other and both sit down on the grass next to Karl. What a bummer. "What did your doctor say?" asks Merle. "He suspects that there's something wrong with the shunt. The valve or the tube... Sometimes there's too little water in my head and sometimes there's too much. The back and forth is no fun," answers Karl calmly.

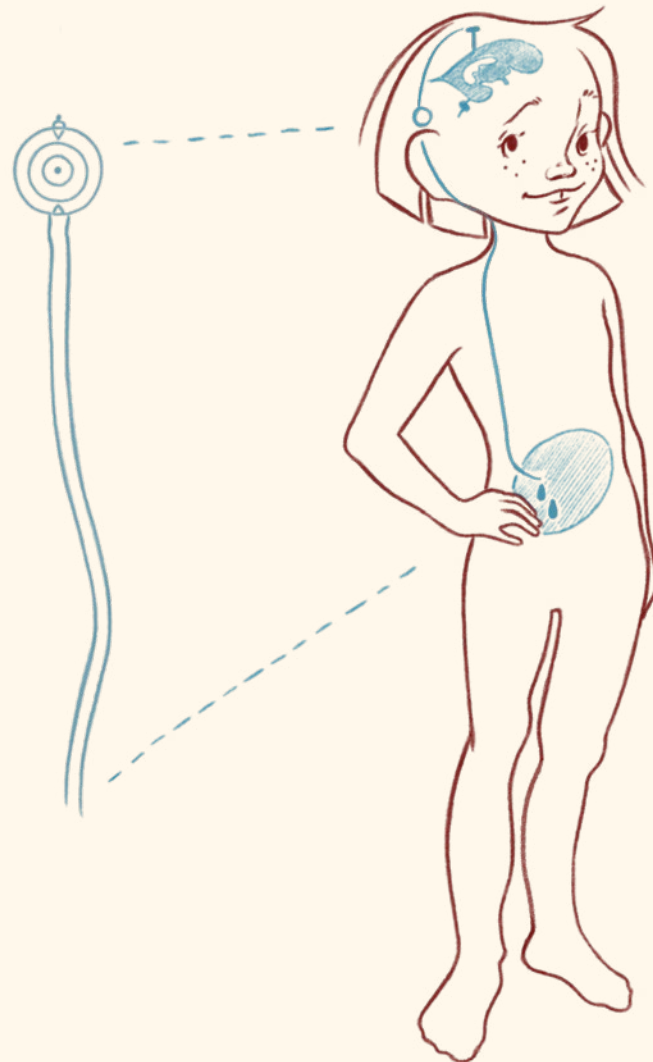
Anton heard the word "shunt" for the first time last year. "And what's his plan?" asks Anton. "Well, what do you think: surgery. He'll probably need a new valve put in. Preferably adjustable from the outside. And if the hose is broken, it'll have to be replaced too. I'll tell you something: I'm scared. Not of the operation - I can manage that - but of the fact that it might not get any better afterwards," Karl admits openly. Merle is surprised because Karl isn't afraid of anything else. Anton totally understands. His thoughts and ideas start to run wild.



ANTON EXPLAINS

WHAT IS A SHUNT?

Doctors say "shunt" when they mean the entire drainage system for cerebrospinal fluid from the head to the abdomen: tube (or as the experts call it: catheter) and valve.



ANTON EXPLAINS

WHAT IS A VALVE / VALVE GUARD?

A valve regulates how much of the excess cerebrospinal fluid is drained off. We call the valve a valve guard because it acts like a guard to ensure that not too much or too little cerebrospinal fluid is drained. Some valves are already very easy to adjust from the outside so that it is possible to change how much cerebrospinal fluid should be drained later on. This can be important if the hydrocephalus changes - for example, because we children are still growing.



ANTON'S IDEA

All three of them go home very thoughtful today. Karl is relieved that he was able to tell Merle and Anton about it, but he is also worried. Karl doesn't want any pity and he doesn't want to have to talk about it again tomorrow.



Merle is confused because she has no idea how she can help Karl. At the same time, she understands how Karl feels better than anyone else.



Anton has quickly asked Karl which valve the doctor wants to use on him and is almost running on the way home because he absolutely has to ask his father for advice on an idea that has just occurred to him.





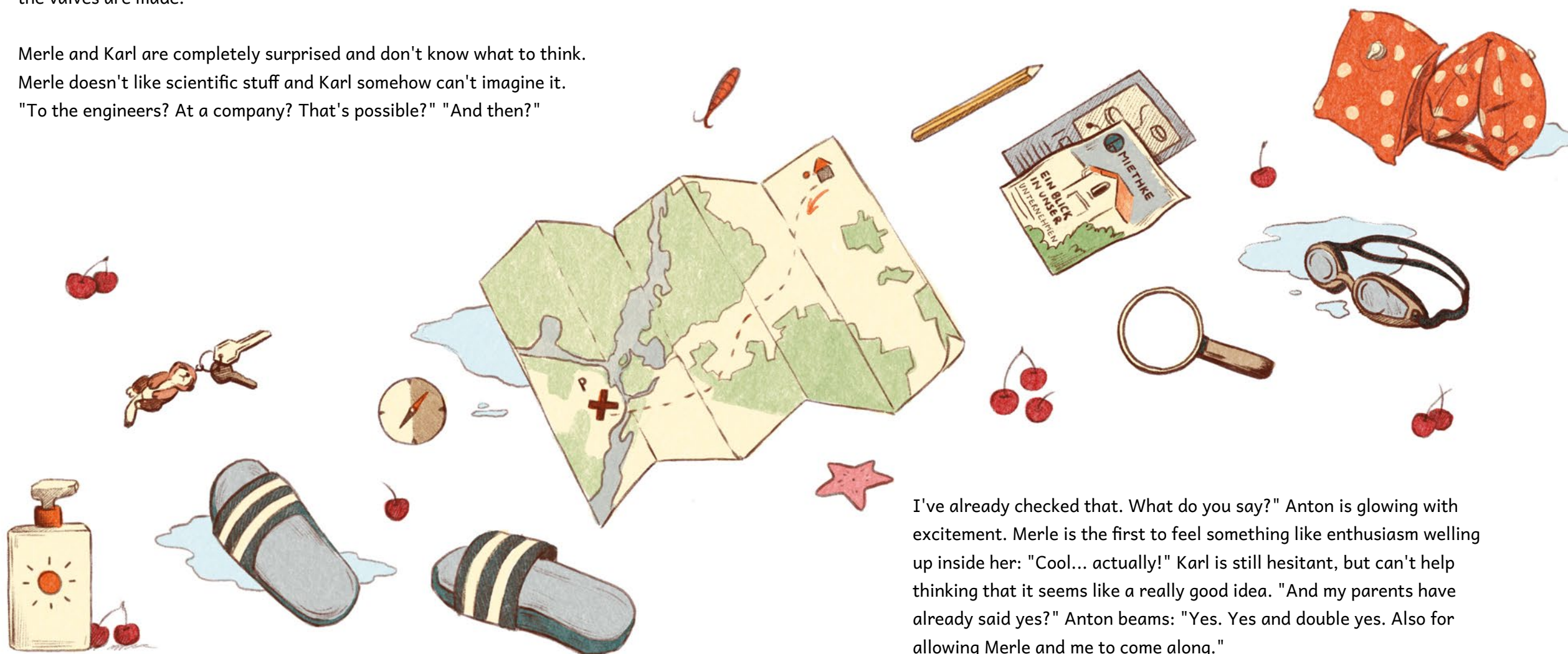
The next day, all three meet at the lake. Anton has been excited the whole time, but neither Merle nor Karl dare ask him about it because they are afraid that he will bring up the subject of hydrocephalus again. Anton approaches all problems scientifically and that's usually great. Today, they both want to have peace of mind about every problem, especially hydrocephalus. Karl is feeling surprisingly well today and wants to go for a swim in the lake and enjoy the day with the two of them.

But then Anton blurts out: "I have an idea!" Merle and Karl are a little skeptical, but have to grin because they have of course already sensed this and now look at their friend questioningly.

"Summer camp is not an option. We'll have to forget about that this summer. But I've spoken to my father and he's spoken to Karl's parents: We could go on an excursion and visit the people who invented the valve guard that Karl is supposed to get during his operation. They would be delighted if we came. My father called the company where the valves are made."

Merle and Karl are completely surprised and don't know what to think. Merle doesn't like scientific stuff and Karl somehow can't imagine it. "To the engineers? At a company? That's possible?" "And then?"

Anton had expected a little more enthusiasm and now tries to explain his idea in a different way: "Well, ... it's a journey and we're doing it together. And we can find out exactly how the valve works and how it's made. Karl might have a better feeling afterwards. And besides, the visit to the company doesn't have to be our only experience... I have no idea what else there might be there. I haven't found out yet, but we'll come up with something. Anyway, it's far enough away that we can spend at least one night there."



"I've already checked that. What do you say?" Anton is glowing with excitement. Merle is the first to feel something like enthusiasm welling up inside her: "Cool... actually!" Karl is still hesitant, but can't help thinking that it seems like a really good idea. "And my parents have already said yes?" Anton beams: "Yes. Yes and double yes. Also for allowing Merle and me to come along."

THE EXCURSION

Just two weeks later, all three are in the car with Karl's parents on their way to the company that invented and manufactured Karl's new guard.

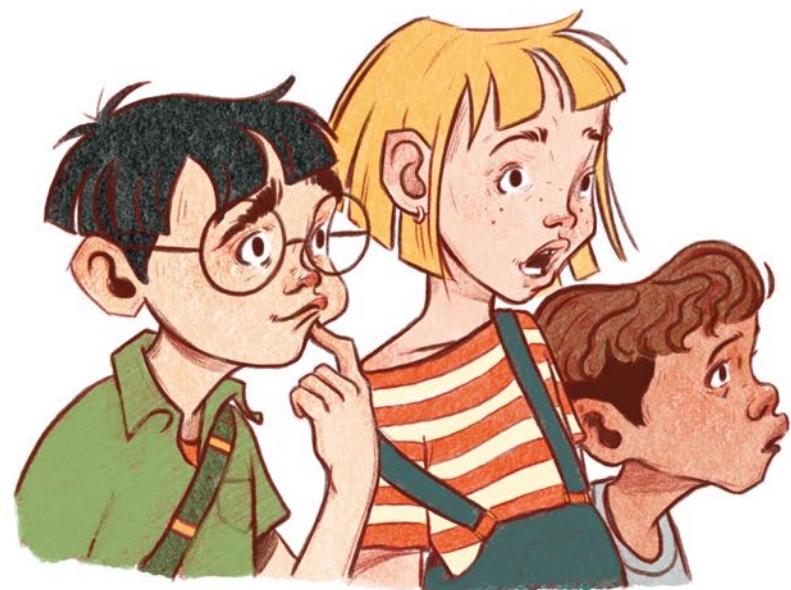


Anton's idea has turned into a solid plan which now excites all three of them and turns into a three-day short vacation. Karl's parents liked the idea of a short vacation just as much as Anton and together they have made further plans for their time together: an amusement park, an experiment museum and a boat trip. That's almost better than summer camp!



When they finally arrive, they are warmly welcomed by two engineers from the company: Susan and Peter.

The three children are still a little nervous and have no real idea what this is going to be like, but they have brought some questions with them. The conversation quickly becomes exciting. Merle, Anton and Karl are particularly amazed when Peter opens a case containing several valves for treating hydrocephalus and the corresponding instruments. "This is what you're supposed to get, Karl," he says, pointing to one of the many valve guards in the case. It's blue! Anton takes over the questions: "Why is the valve blue? How does it work? Why is the doctor planning this for Karl? What can this do better than his old valve guard?"





ANTON EXPLAINS

HOW DOES KARL KNOW HOW HIS VALVE IS ADJUSTED?

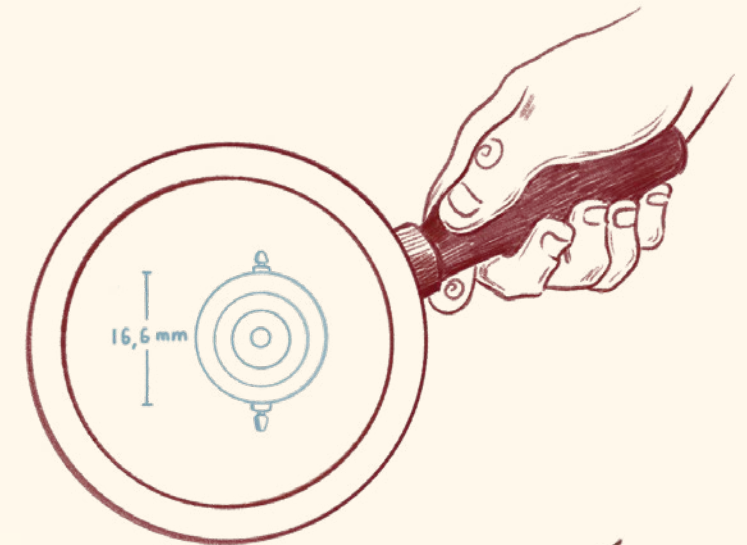
The *M.blue* can be checked from the outside with a measuring instrument and also without X-ray control to ensure that it is set to the correct pressure level. There is also a patient passport for this purpose in which the pressure level and the implanted valve are documented. Karl should always carry the passport with him.



ANTON EXPLAINS

HOW BIG IS THE BLUE VALVE THAT IS IMPLANTED IN KARL?

The *M.blue* from MIETHKE is round and has a diameter of 16.6 mm and a height of 4.2 mm – so it is slightly smaller and slightly thicker than a 20-cent piece (EURO).



ANTON EXPLAINS

CAN KARL CHANGE OR ADJUST THE PRESSURE LEVEL OF HIS VALVE HIMSELF?

No, only doctors who have been specially trained for this are allowed to do this.



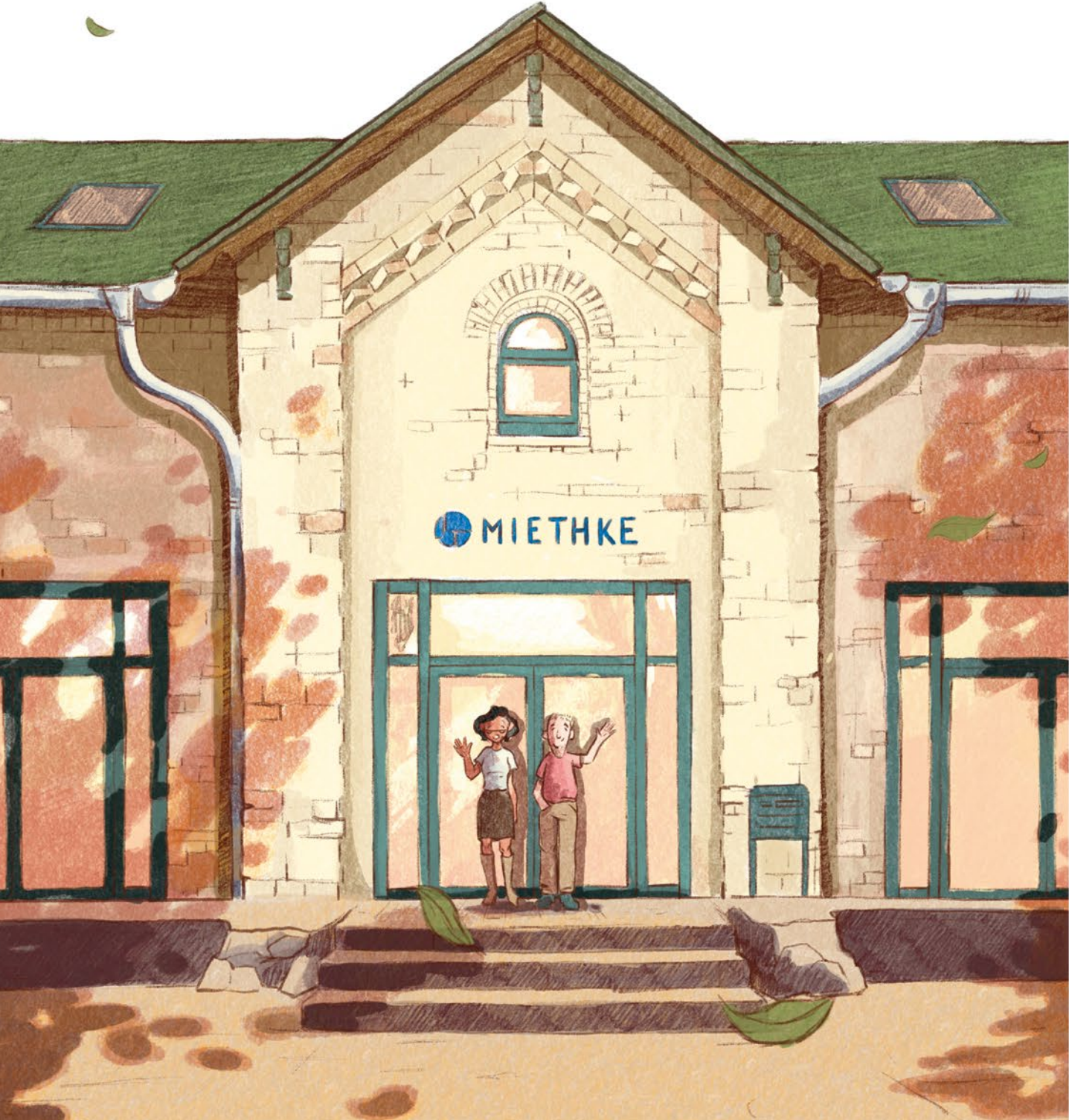
The three of them learn that there are valve guards that can be adjusted from the outside. They learn that gravity plays a role and what can be important in order to be as active as healthy people. And Karl is ultimately very active... actually... when he feels well. The very small valves are presented to them as large models, so that they can look inside the valves and see exactly how they work. They are allowed to touch them and, because they are models, adjust them themselves - just like a doctor. Anton is fascinated by the technology. Merle almost feels like a doctor herself and is surprised at how much she likes it and Karl realizes that it helps him to understand everything better - and he thinks blue is kind of cool. Like the sea. Like the sky.



Finally, Susan and Peter show them the really big machines that are used to make the tiny individual parts that make up a valve and they are also allowed to walk through all the other stations involved in making a single monitor. They are amazed at how many steps and people are involved and how often each step is checked in between - it feels good. Karl's mother now also knows that she can call here at any time if she has a question and that they can even give her the names of clinics in vacation destinations that will be very familiar with Karl's valve.



Nobody expected a visit to a company to be so exciting.



And their short vacation got even better over the next few days thanks to the great excursions.

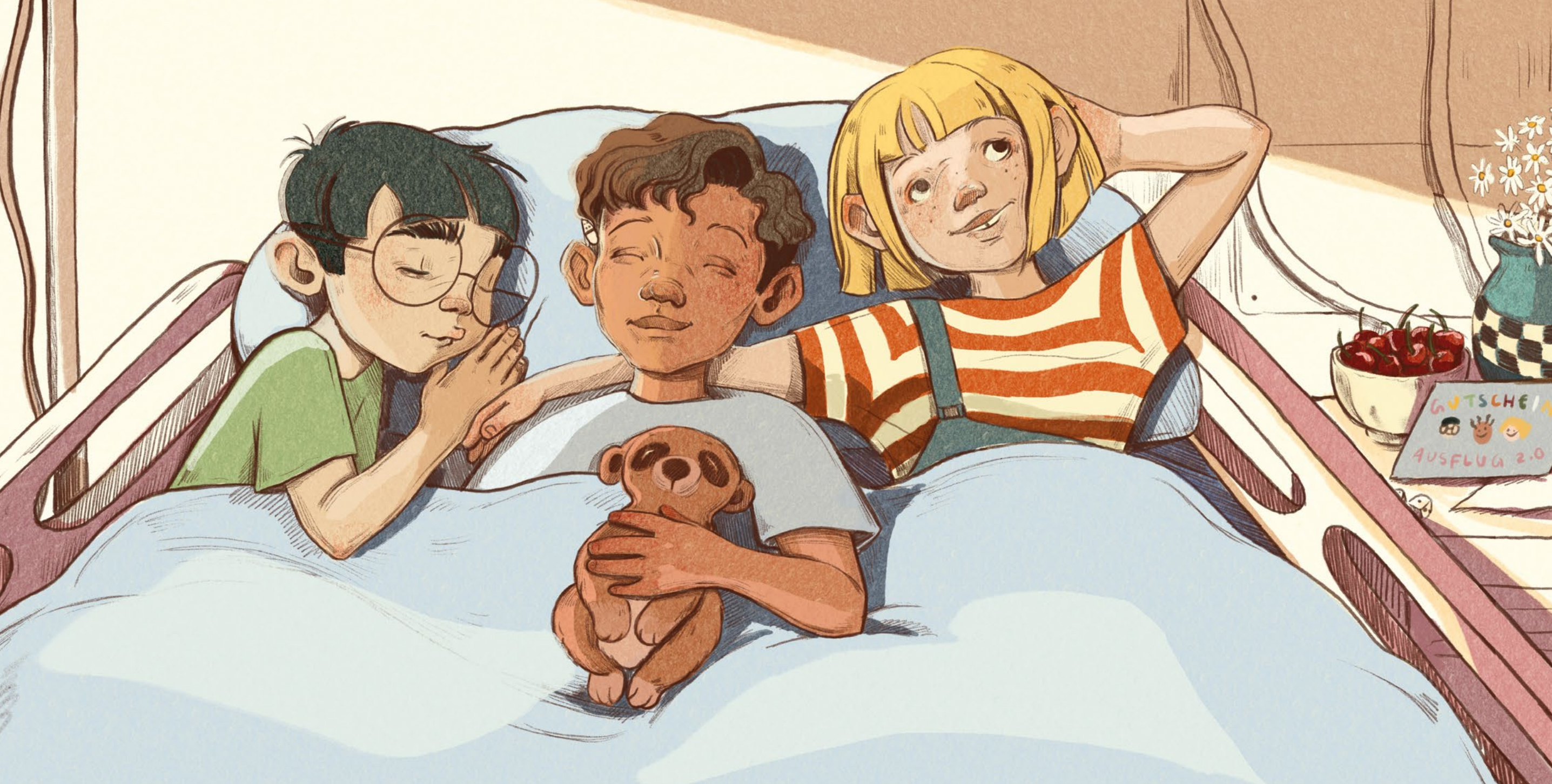
On the way home in the car, all three are very quiet and lost in their own thoughts. Anton is a bit proud that his idea was such a success. He thinks that engineering is actually a great profession for him. Merle watches Karl, who has his eyes closed and looks like he is sleeping, and she hopes that he feels less afraid now. Karl is not asleep at all. He just wants to think about everything again in peace and so he has closed his eyes. He is so glad to have the two of them by his side as friends. Although he has learned a lot, he is still afraid. But he no longer feels so alone with it and understands many things better now. Physics might not be as pointless as it sometimes seems to him at school. That also feels good.



KARL'S GUARD



Just a few weeks later, Karl has come through the operation well and is lying in his hospital room, relieved and surrounded by Merle and Anton. The blue valve is working well and he is already feeling much better. So now he has a blue valve guard and it should keep working hard! Karl is really looking forward to finally being able to go to basketball training regularly again, not missing any more get-togethers with Merle and Anton and perhaps actually being able to go to a camp with them during the next vacation. It feels like it could all be possible again soon.



Merle lies next to her two friends on Karl's bed and thinks about the fact that Anton and she are also guards for Karl.

And she happily realizes that they are all guards for each other. Hopefully forever.

FREQUENTLY ASKED QUESTIONS TO MIETHKE

DO I NEED A PATIENT PASSPORT TO TRAVEL TO OTHER COUNTRIES?

No. Nevertheless, we recommend that you always have your passport with you so that you can identify yourself as an implant patient and have all the important information with you in an emergency.

CAN I FLY WITH A MIETHKE VALVE?

Basically, yes. Flying or the pressure differences in the airplane have no effect on the functioning of our valve systems. We recommend that you always have your patient passport with you, e.g. so that you can identify yourself as an implant wearer at the security check.

CAN I DIVE UNDER WATER WITH MY MIETHKE VALVE?

As is so often the case, what feels good is allowed. What doesn't feel good is not. And in any case, the suitability for diving - as with healthy people - should be agreed upon with the treating doctors beforehand.

WHO CAN I ASK AT MIETHKE ABOUT THE PRODUCTS?

Medical device consultants!
Simply call
0049 331 620830
or write to:
questions@miethke.com

HOW DO MIETHKE VALVES WORK?

Our website is the best place to find out:
www.miethke.com
or our MIETHKE app:



I HAVE TO GO FOR AN X-RAY. IS THAT A PROBLEM WITH MY MIETHKE VALVE?

No. X-ray examinations are harmless for all MIETHKE valves and have no influence on the functionality of our valves.

HOW LONG DOES A HYDROCEPHALUS OPERATION TAKE?

The duration of the implantation of a shunt depends on several factors and cannot be answered in general terms. As a rule - without special incidents - 30 to 60 minutes can be assumed.

CAN MY MIETHKE VALVE GET OUT OF ADJUSTMENT DURING AN MRI EXAMINATION?

No. MIETHKE valves are compatible with MRI devices up to 3 Tesla. This means that our valves do not move unintentionally during an MRI examination.

CAN I DO INTENSIVE SPORTS WITH MY MIETHKE VALVE

Yes, if this has been discussed with your doctor beforehand. It is important that you feel well and that no typical pressure symptoms occur.

WHAT MATERIALS ARE MIETHKE VALVES MADE OF?

Almost all individual parts of a MIETHKE valve are made of biocompatible titanium. This makes them robust and durable.

OUR MEDICAL PRODUCT CONSULTANTS

If you have any questions about the valve guards, their inventors, how they are made or how they work, give us a call or send us an email. Or drop by with your parents if you happen to be near Potsdam. Our medical product consultants will be happy to show you exactly how the valve guards are manufactured. We look forward to your visit. Give us a call and we'll find an appointment.

If you as a parent still have questions, you are welcome to contact our medical product consultants at any time: +49 331 620 83-0
questions@miethke.com // www.miethke.com



Christoph Miethke



Roland Schulz



Josefine Kehl



Michaela Funk-Neubarth



Thammo Weise



Jan Mügel



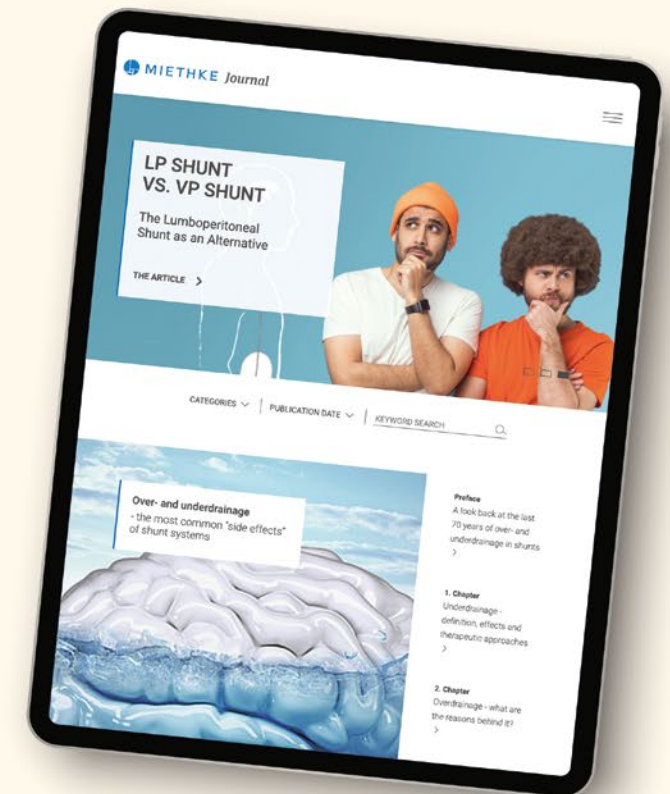
ANTON'S TIP THE MIETHKE JOURNAL



Do you or your parents still have unanswered questions or would you like to dive deeper into the scientific and technical background and issues surrounding hydrocephalus? Then take a look at our MIETHKE Journal. The journal explains shunts, catheters and functions in more detail from a technical perspective and answers the questions that doctors and patients often ask themselves at some point during hydrocephalus treatment. The MIETHKE Journal is written by people at MIETHKE because hydrocephalus is their topic. Every day. Full time.



HERE YOU WILL FIND
 MIETHKE Journal





ANTON'S TIP

PATIENT ORGANIZATIONS

National patient organizations are a very good point of contact, which also offer exchange, seminars, experience reports and much more. In Germany, we recommend contacting the Arbeitsgemeinschaft Spina Bifida und Hydrocephalus, where you can find extensive information about rare diseases, treatment options and further support. In the UK there is Shine or Harry's HAT in the USA the Hydrocephalus Association. It is worth looking for such organizations in your own country.

Visit the Patient Organizations:

www.asbh.de // www.shinecharity.org.uk // www.harrys-hat.org // www.hydroassoc.org



ANTON'S TIP

MORE ABOUT THE INVENTORS OF MERLE, ANTON AND KARL

If you want to find out more about Merle, Anton and Karl, take a look at their website. Here you will find information about how the story came about, who drew the three of them and why this story exists at all.



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Christoph Miethke GmbH & Co. KG
Ulanenweg 2
14469 Potsdam
Germany

+49 (0) 331 620 83-0
info@miethke.com
www.miethke.com

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Author: Michaela Funk-Neubarth
Illustrations: Mingliang Sun
In collaboration with Prof. Lisa Bucher,
FH Potsdam, Department of Design.

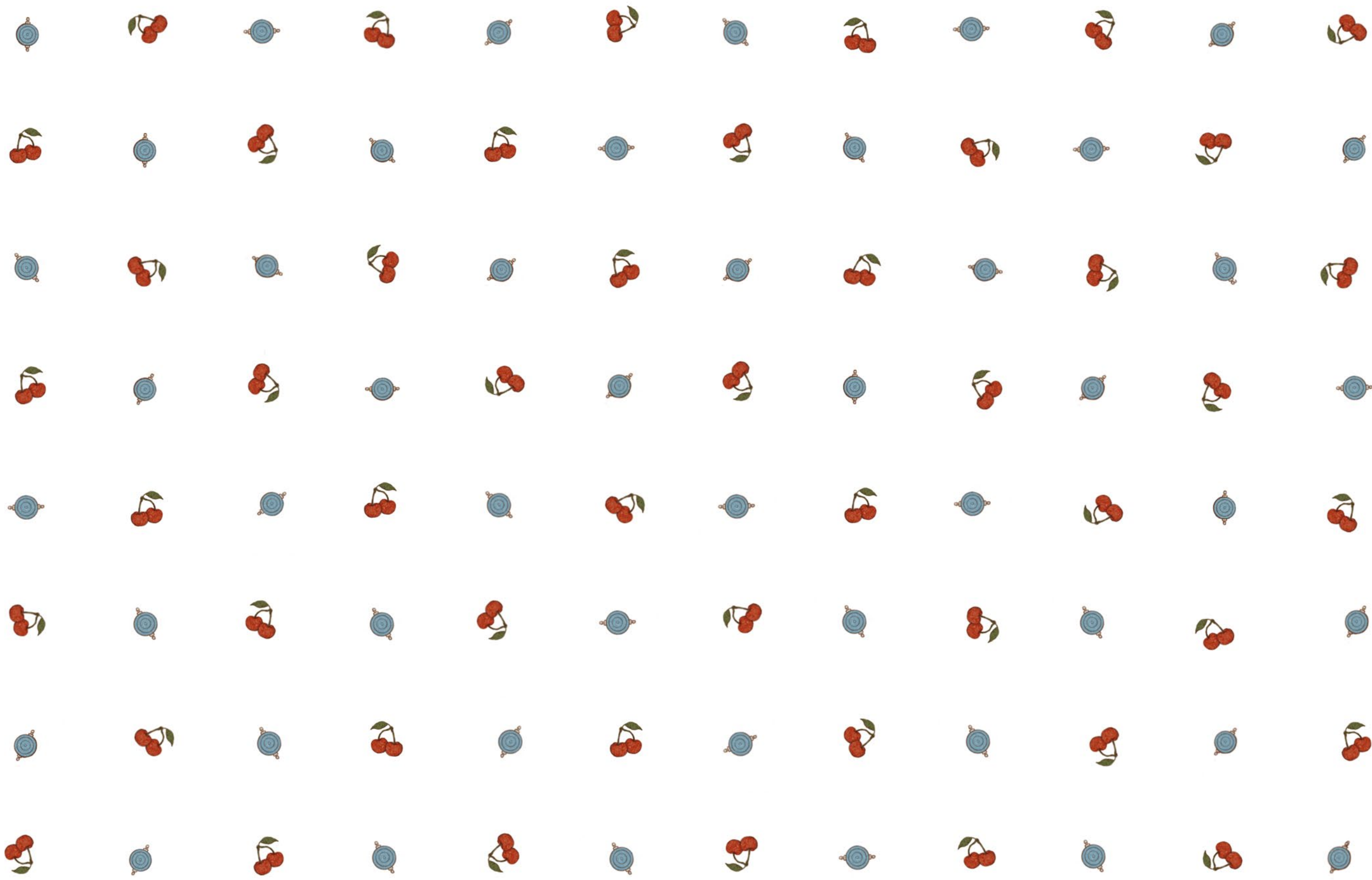
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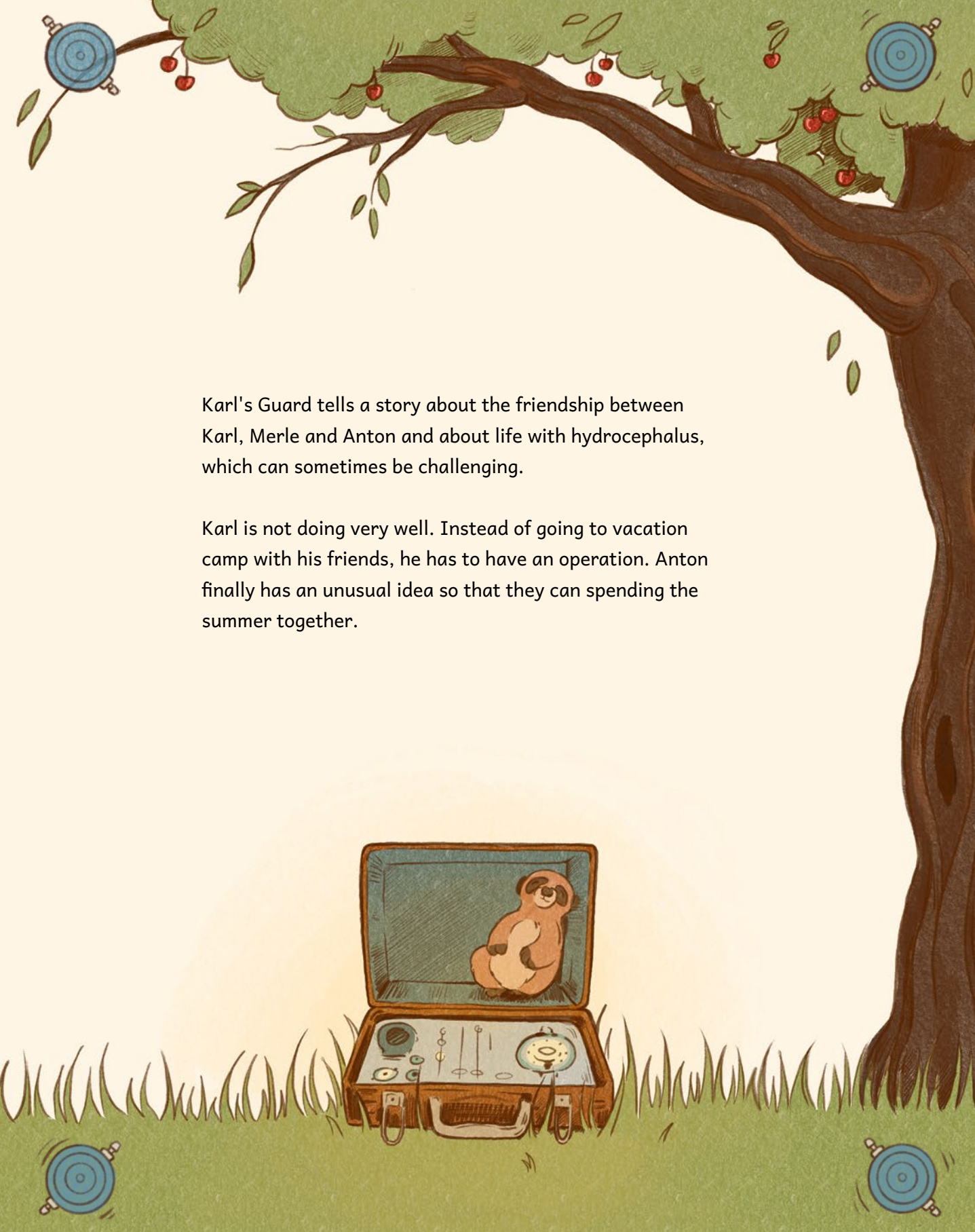
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A large, stylized tree with a thick brown trunk and green foliage. Several red cherries hang from the branches. Four blue circular objects with concentric rings and small protrusions are positioned around the tree: two at the top corners and two at the bottom corners. The background is a light, warm yellowish-brown.

Karl's Guard tells a story about the friendship between Karl, Merle and Anton and about life with hydrocephalus, which can sometimes be challenging.

Karl is not doing very well. Instead of going to vacation camp with his friends, he has to have an operation. Anton finally has an unusual idea so that they can spending the summer together.

