

I AM BRAVE

AN HCU FRIENDLY TALE



WRITTEN BY LIZ CARTER

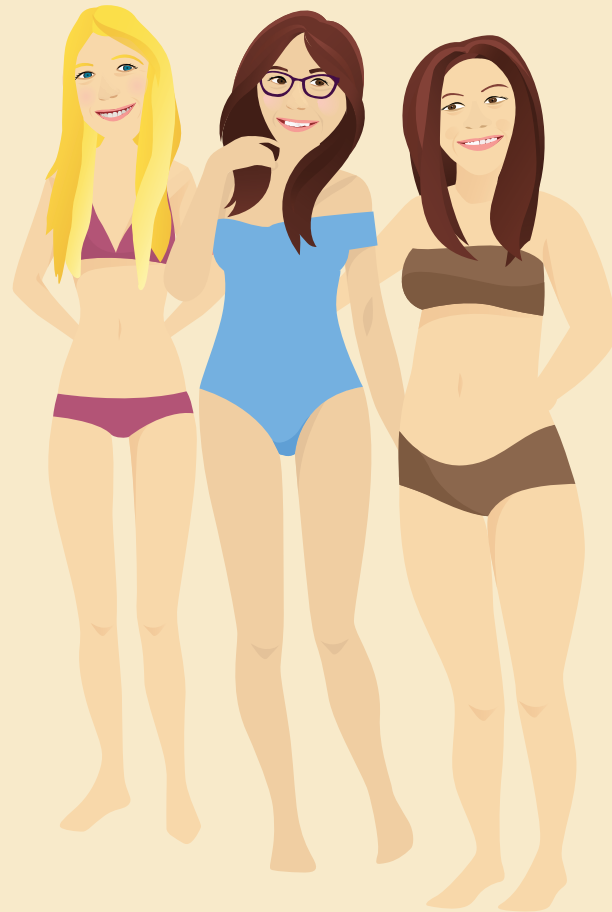
ILLUSTRATED BY JANA MALECEK

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“I’m going to miss you guys so much! Ugh, why did we have to move? I mean, I know we aren’t technically THAT far away, but I don’t want to go to a new school!”

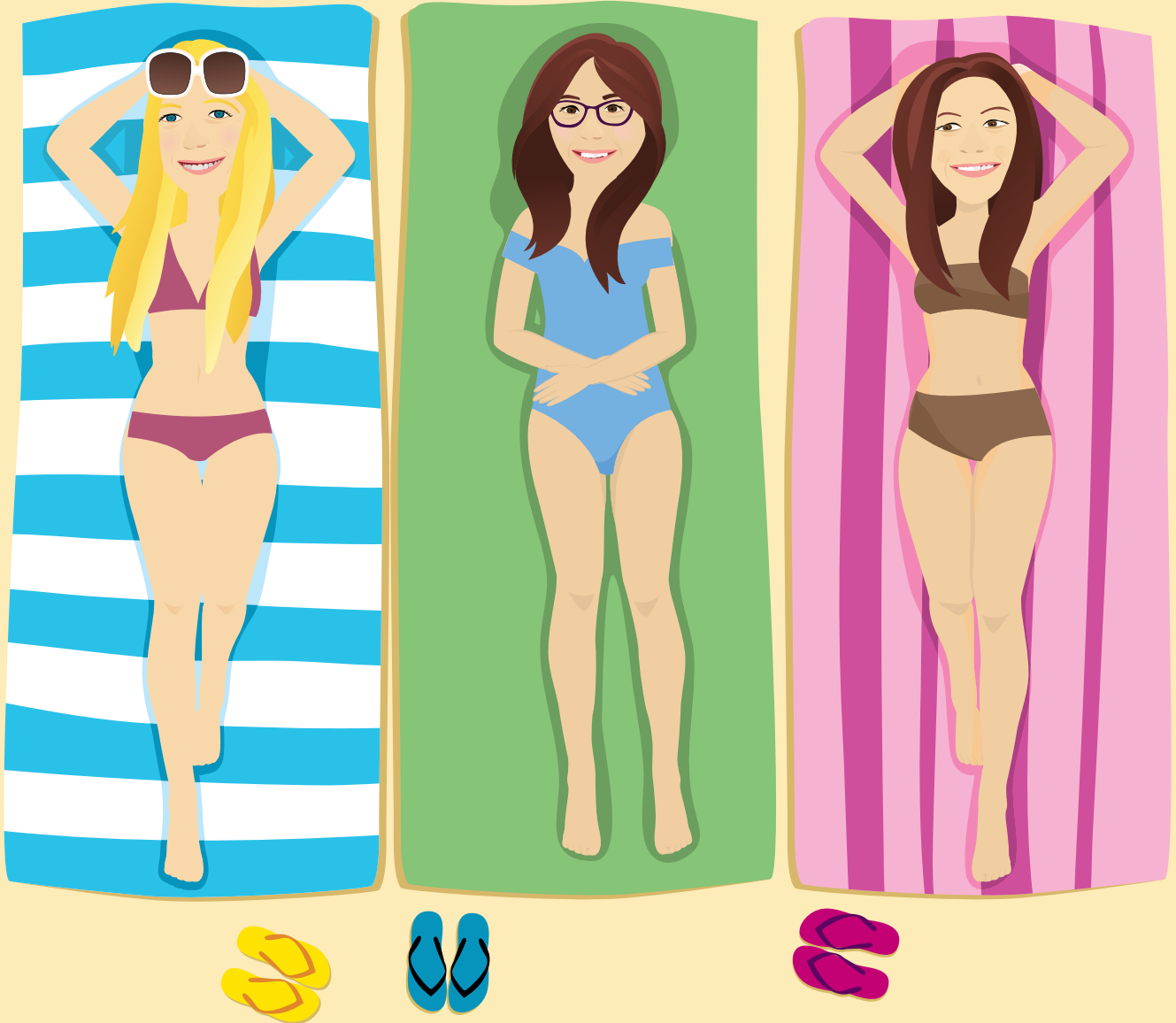
“Don’t worry, Colbie, you know we will still hang out on the weekends.”, replied Gabbi.

“Yeah, we can go rollerblading on Saturdays and have spend the night parties like we always do.”, added Josie.



“Promise you guys won’t forget about me?” Colbie asked, looking at her two best friends, who she had met when they were all in the same kindergarten class at Brookview Elementary.

“Promise!” the two girls said together, their voices echoing through the air.



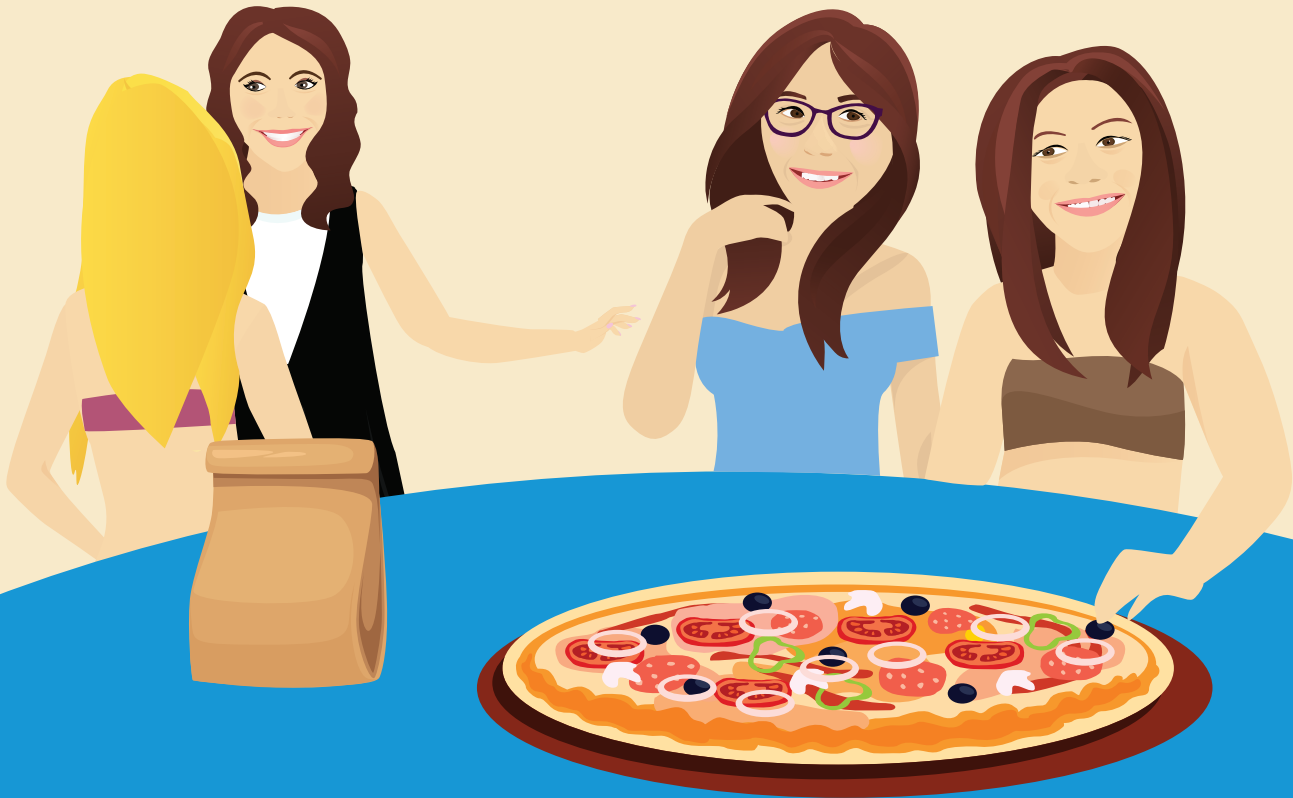
“Come on, let’s jump in!”, yelled Josie, grabbing Colbie’s arm and pulling her towards the pool. Colbie and Gabbi especially loved to meet at Josie’s house after school and on the weekends, where they would swim in the pool for hours, or until they got bored and decided to go in and watch their favorite shows on Netflix. Today they were having one last get together before starting a new school year the very next day.



“Girls, time for lunch!”, Josie’s mom yelled out. “Time to dry off!”
“Woohoo! I’m starving!”, said Josie. “Me too”, Colbie and Gabbi said at the same time, before looking at one another and saying “jinx!” “Last one there has to clean up!”, yelled Gabbi. And the three girls took off, racing for the door.



The smell of pizza filled the kitchen. “I call the biggest piece!” said Gabbi, reaching for a plate. As Gabbi and Josie began piling slices of pizza onto their plates, Colbie walked over to the refrigerator to take out her lunch-box. “Ms. Ruth, can I borrow a spoon? I forgot to pack one for my yogurt.” “Of course, Colbie...help yourself”, replied Josie’s mom, motioning toward a drawer next to the sink.



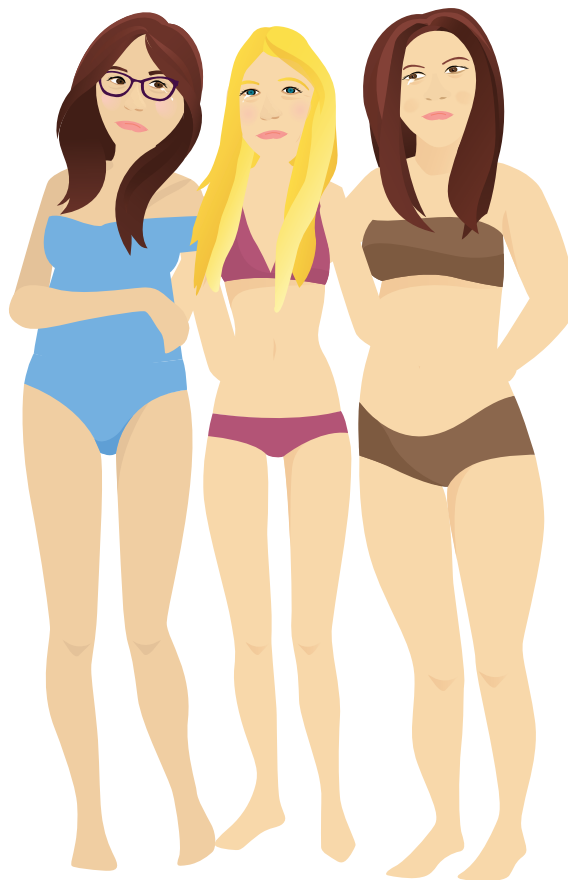
As the girls sat down to eat, Colbie started to unpack her lunch. “Yes! A new flavor of low protein yogurt - raspberry vanilla! I was starting to get a little tired of the blueberry.” “Can I taste?” asked Gabbi, reaching towards Colbie’s spoon. “Sure...you’ll like it”, said Colbie, pushing the cup of coconut milk yogurt toward Gabbi. “Delish!”, Gabbi said, shoving a heaping spoonful into her mouth.



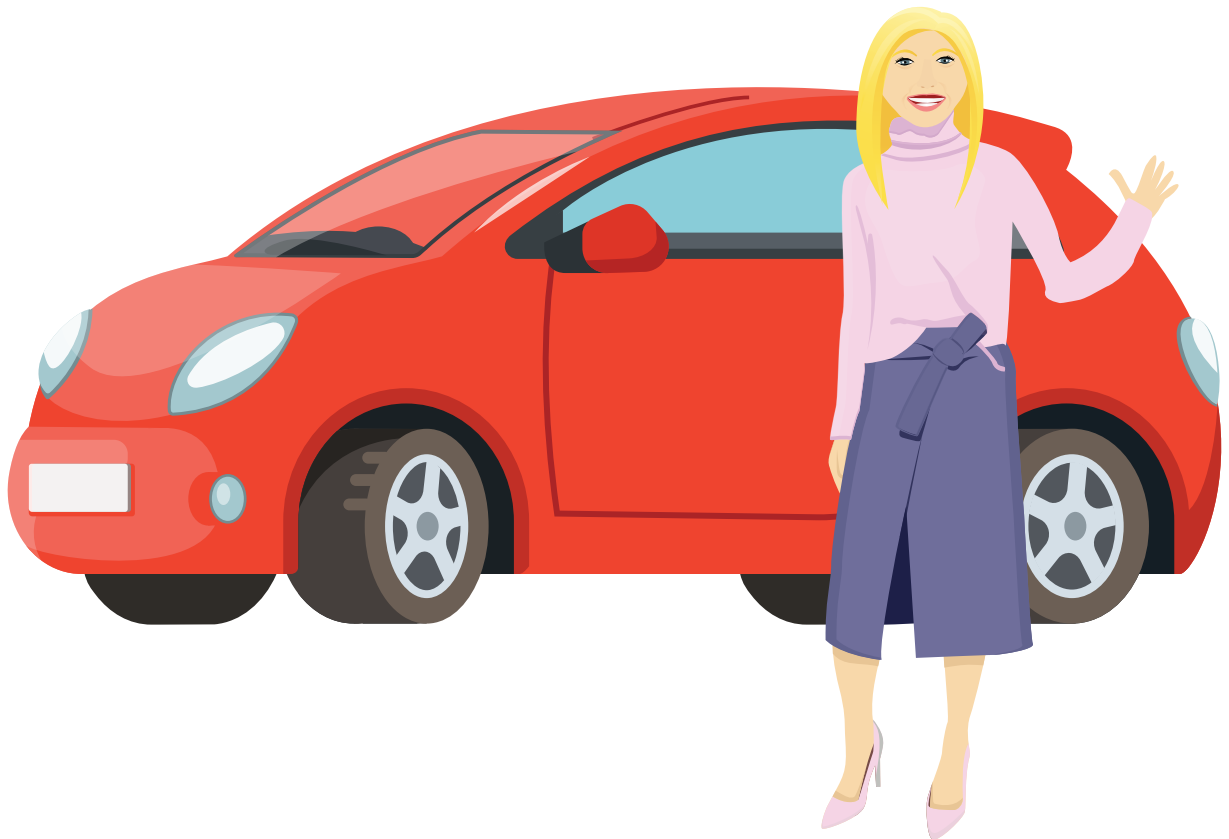
“I’ll have just one more slice!”, said Josie, opening the box of pizza and looking inside. “You better save room for cake!”, yelled Colbie. Colbie’s mom had baked and sent over a gluten-free vanilla cake, topped with whipped vanilla icing and sprinkles, that happened to be low in protein. “Duh!”, replied Josie. “Your mom’s cakes are the best!”.



As the girls finished up their slices of cake, the doorbell rang. It was Colbie's mom. Colbie took one last bite of cake and looked at her friends. She felt a sudden rush of emotion come over her and tears began to fill her eyes. Noticing her sudden change of emotion, Josie and Gabbi both swooped Colbie into a giant hug. "NOTHING is going to change, Colbie. We are always going to be best friends," said Gabbi. "Yeah...we'll always be here," echoed Josie, looking Colbie straight in the eyes, and wiping away her tears. Colbie knew that her two best friends meant what they said, and she felt a bit of her sadness melt away.



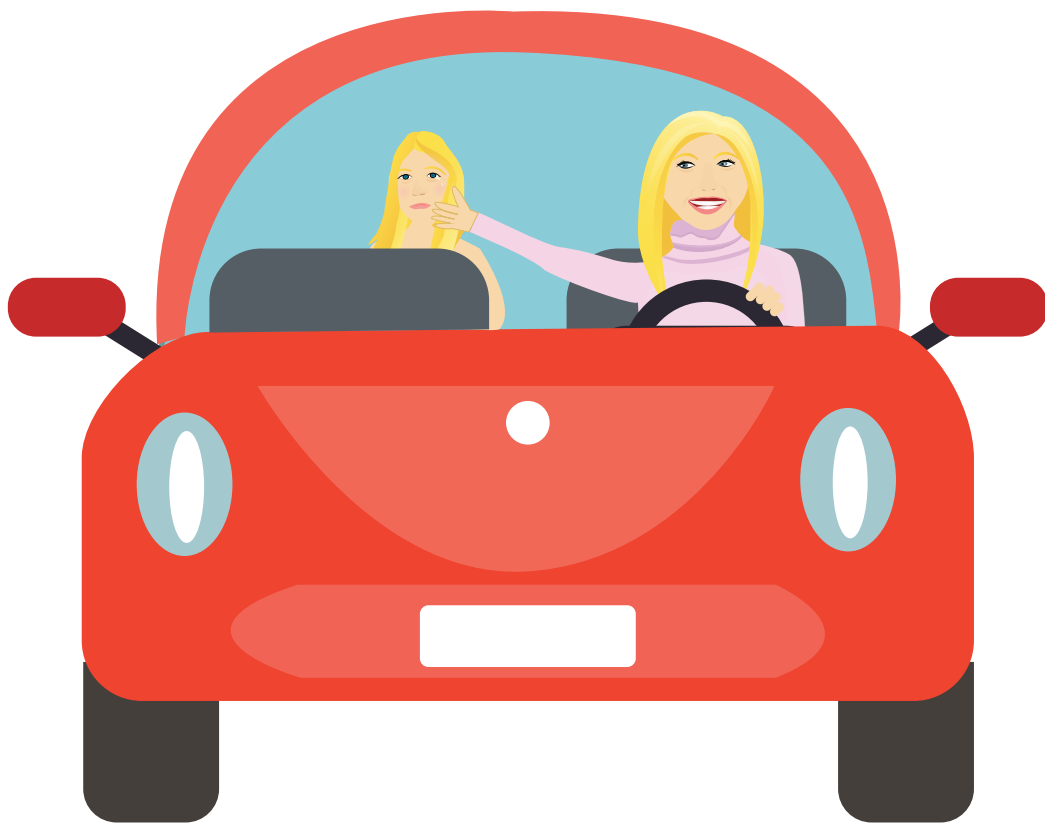
“Colbie, time to go honey!”, said Colbie’s mom, pointing to her watch. Colbie said one last goodbye to her friends, and got into the car. As the car engine started, Colbie looked out of the window. She took a deep breath, and waved goodbye to Josie and Gabbi.



“Did you have a good time?” Colbie's mom asked. “Uh huh...”, Colbie replied quietly. Noticing that Colbie didn't seem her usual bubbly self, her mom asked “Is everything ok, honey?”. “I'm just nervous about school tomorrow, ” Colbie replied softly. “What if I don't find new friends? What if the other kids ask me questions about my Homocystinuria or make jokes about my formula? They don't know me like Josie and Gabbi and all of my friends from my old school do”.

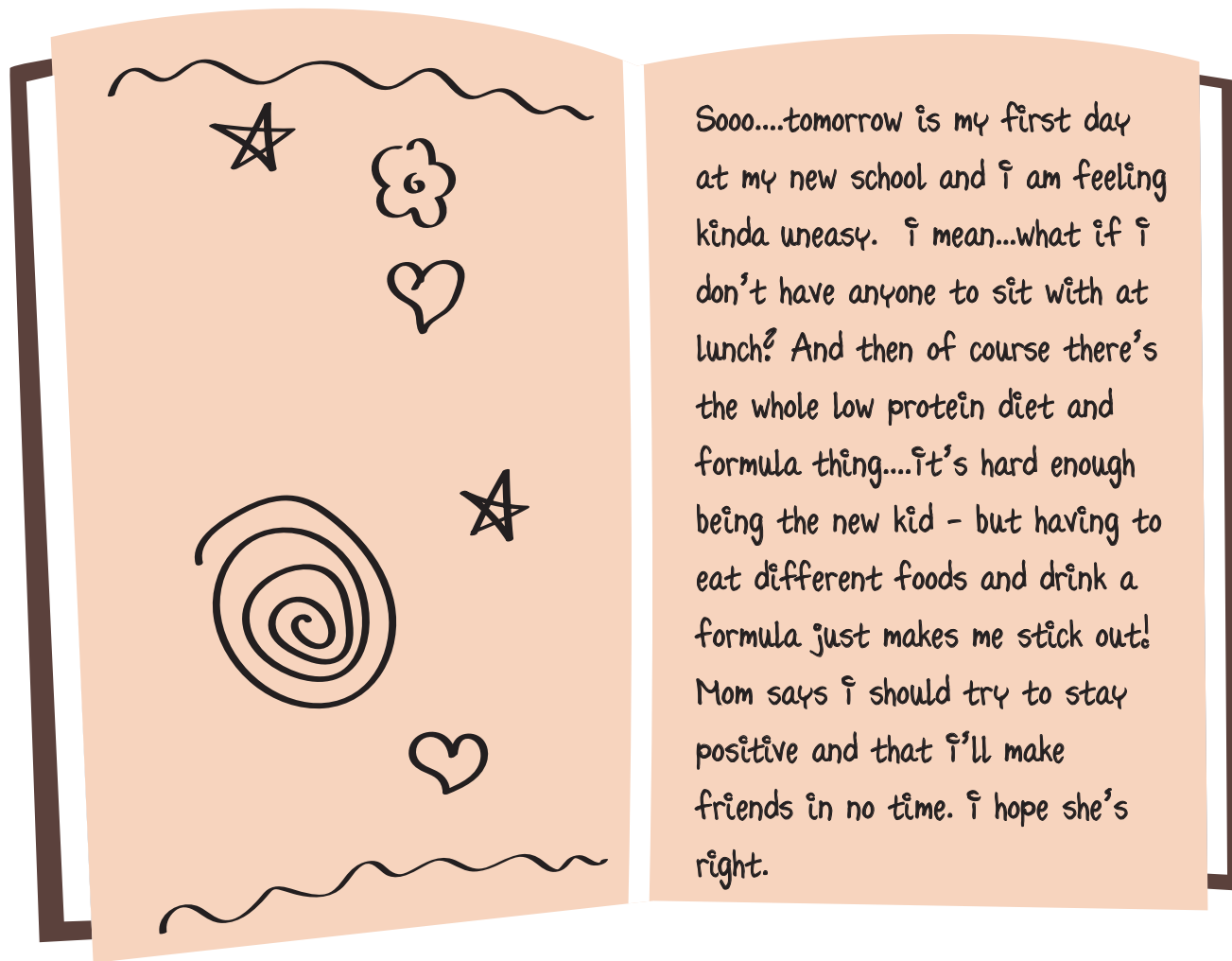


Stopping at a red light, Colbie's mom looked over at her and put her hand gently on Colbie's cheek. "Oh sweetheart...don't worry. You will make friends in no time because you are a kind-hearted girl, and people see that. Remember...your HCU is only a small part of who you are, and is not something to be ashamed of. You just tell them that you are rare...and special!". "Moooom...", Colbie replied back, rolling her eyes, but allowing a smile to stretch across her face.



Colbie's mom pulled into the driveway. As soon as the car parked, Colbie jumped out, flew through the front door of her new house, and ran upstairs to her room. Feeling nervous and a bit overwhelmed about starting fresh at a new school the next day, Colbie decided that she just needed some alone time to relax. She plopped down on her bed and reached for the little pink notebook on her bedside table. Grabbing a pen out of the drawer, Colbie began to write in her journal. Colbie loved to write, and journaling was a way for her to get out her thoughts and feelings, which usually helped her to feel better.





Sooo....tomorrow is my first day at my new school and i am feeling kinda uneasy. i mean...what if i don't have anyone to sit with at lunch? And then of course there's the whole low protein diet and formula thing....it's hard enough being the new kid - but having to eat different foods and drink a formula just makes me stick out! Mom says i should try to stay positive and that i'll make friends in no time. i hope she's right.

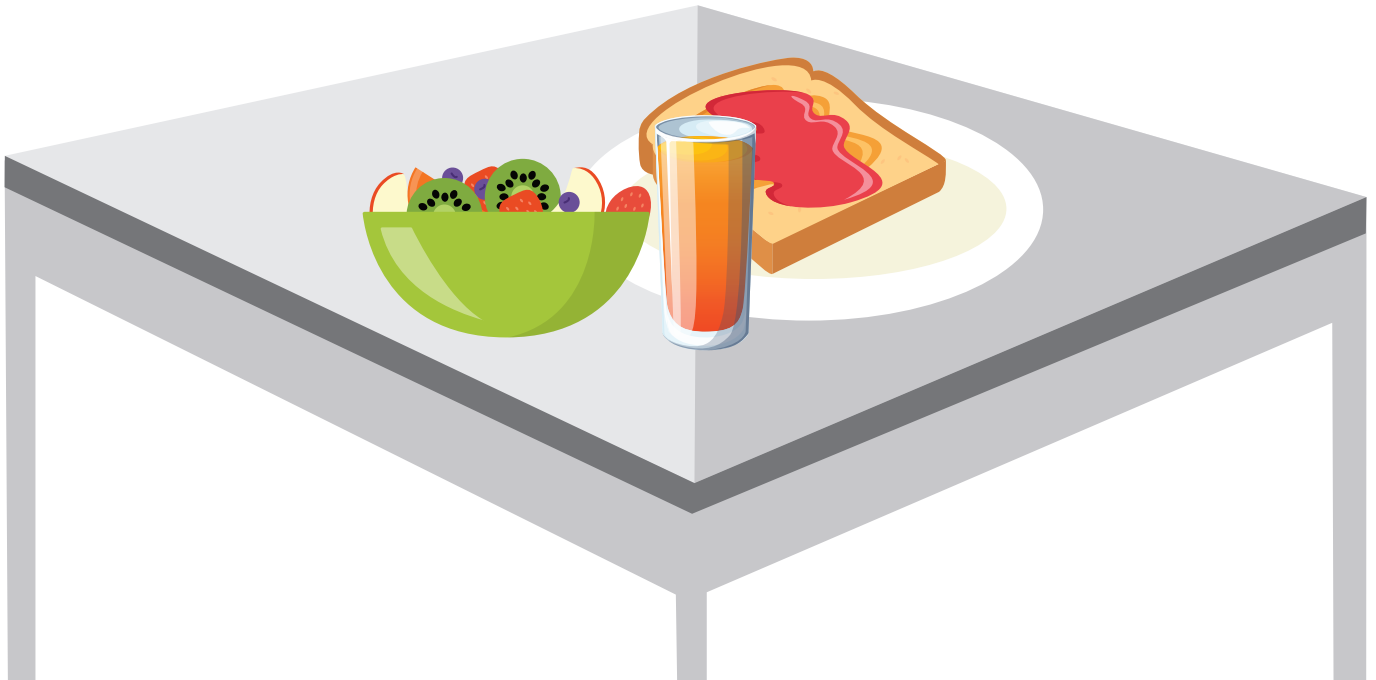
That night, as Colbie got ready for bed, she laid out her outfit for the next day. She brushed her teeth and hugged her parents goodnight. And as she laid her head down on the pillow, she reminded herself of what her mom and dad had always told her - “I am brave...and I can do hard things.” And she drifted off to sleep.



“Colbie...time to wake up for your first day of school...”, Colbie heard her mother whisper into her ear. Colbie pulled the covers up over her face and rolled over. “Just five more minutes, mom.”, Colbie said, as she let out a yawn. “No, honey. We don’t want to be late - Rise and shine!” “Ok, ok!”, yelled Colbie, throwing the covers aside and stepping out of bed.



When Colbie came down for breakfast, she noticed that the smell of something burning filled the air. “Dad, did you burn the toast again?” “You know me...burned bread is my specialty”, chuckled Colbie’s dad. Colbie always liked to eat the same thing for breakfast on school days: a piece of low protein toast with butter and jelly and a small bowl of fruit.



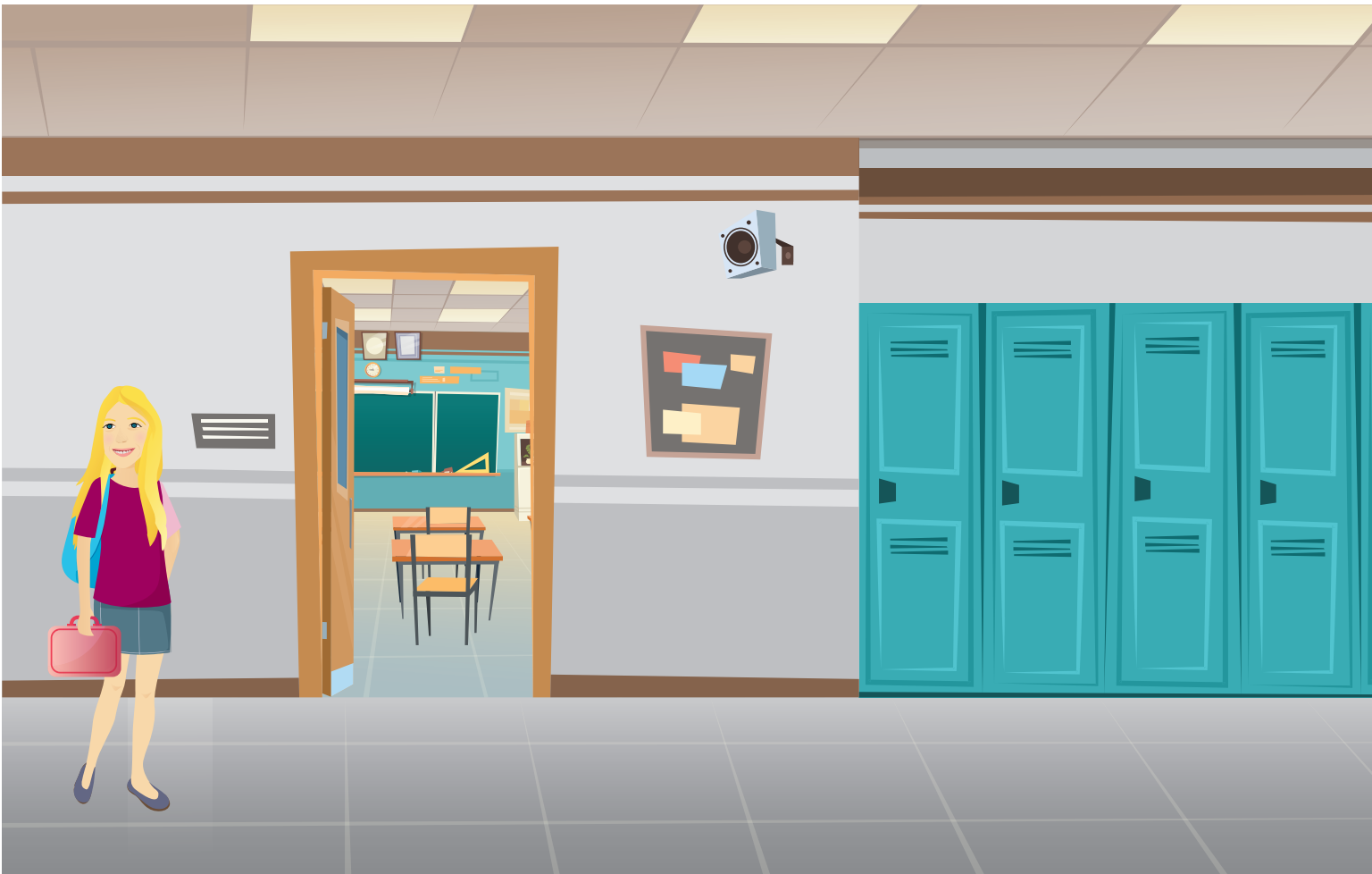
After finishing off the last bite of fruit, Colbie took her vitamins: B6, B12 and Folic acid. She then mixed her Betaine with a bit of juice, and slugged it down. Colbie mixed her formula with some chocolate Ovaltine, as she always did, to drink on the ten minute car ride to school.



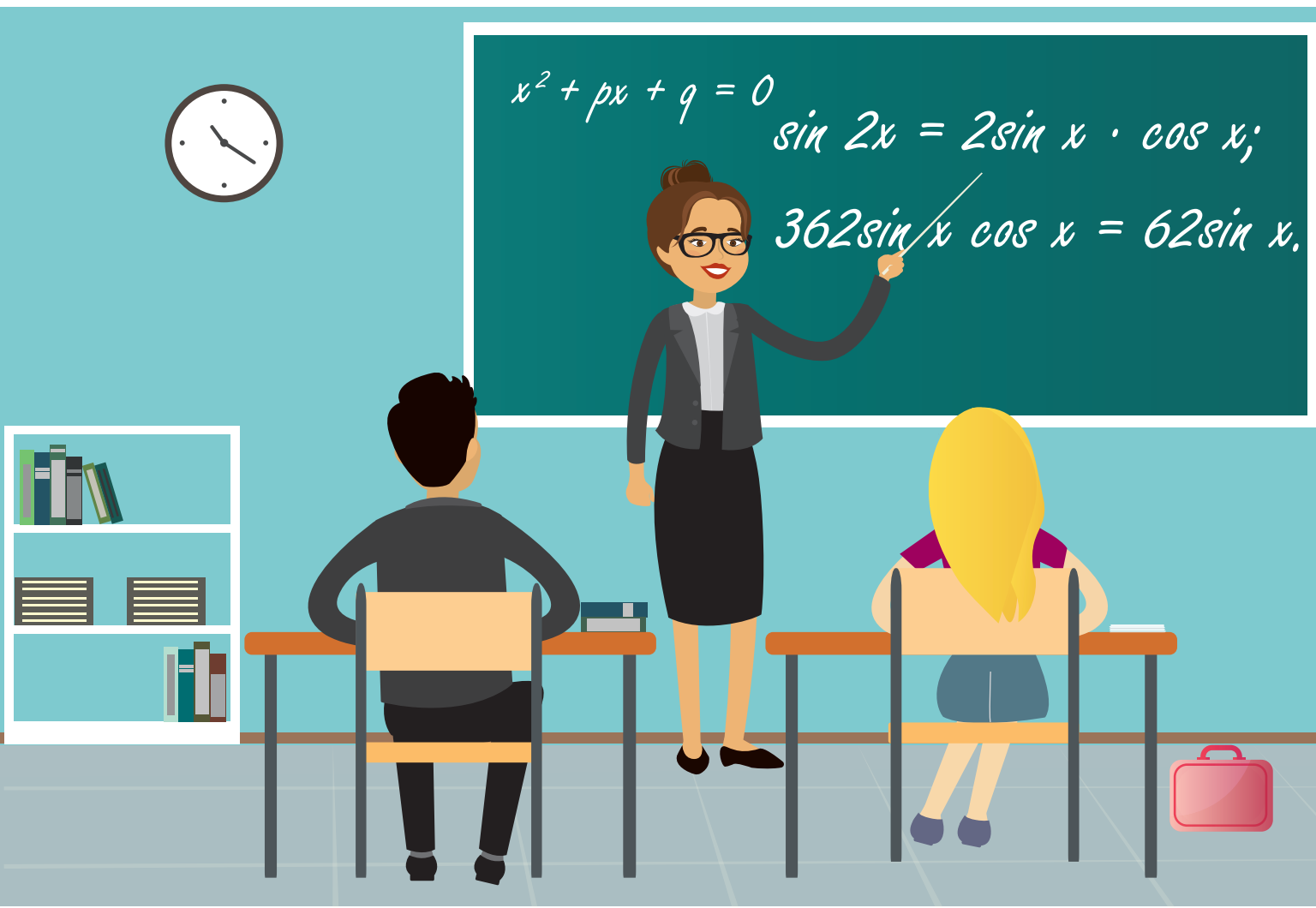
“Ready, mom!” Colbie yelled, grabbing her bookbag and scooping her lunchbox off of the counter. “Guess it’s now or never...”, Colbie whispered under her breath as she headed out the door to her mom’s car.



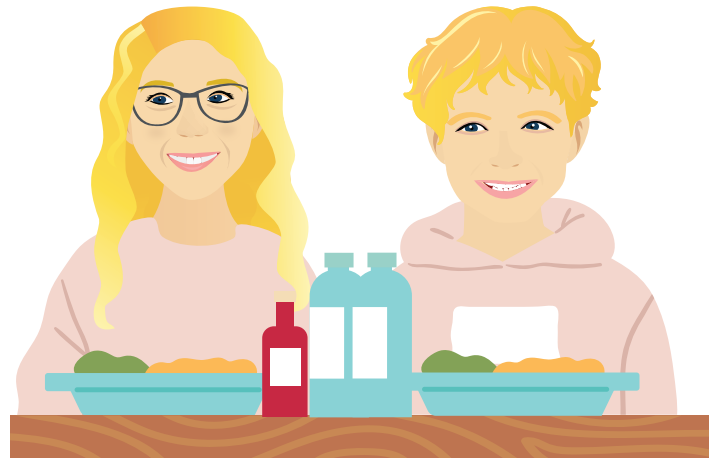
When Colbie arrived at school, she felt butterflies in her stomach. As she walked down the hallway of her new school toward her classroom, she took another deep breath. “I am brave, and I can do hard things...”, she reminded herself.



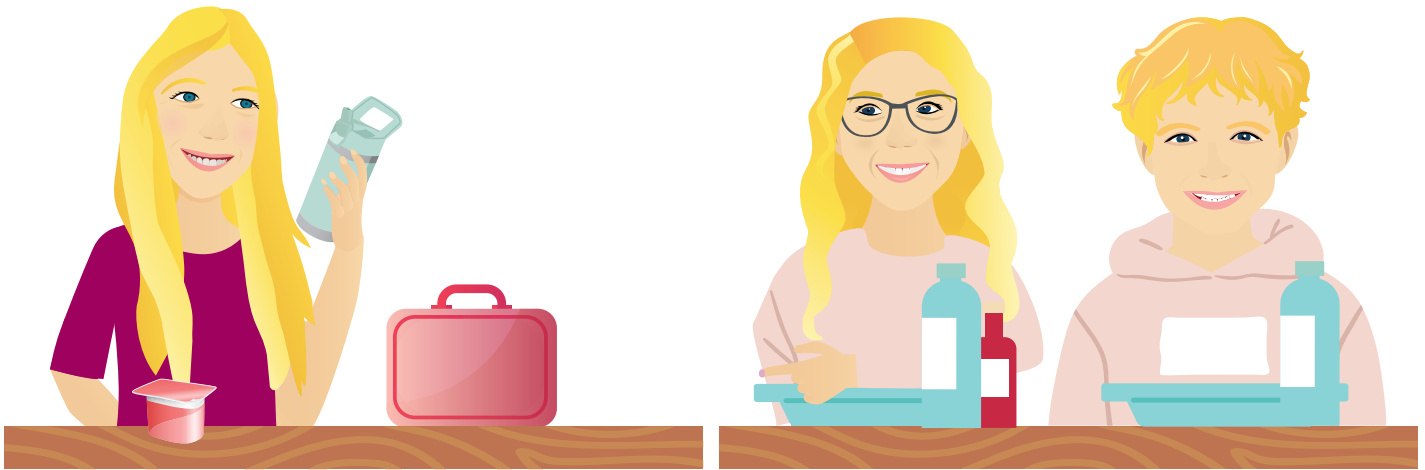
As lunchtime grew nearer, Colbie began to have thoughts swirling around in her head. “Who will I sit with in the cafeteria?” “What if they ask questions about my diet and formula?” “What if they tease me for being different?”. Her thoughts were interrupted by the sound of her teacher, Mrs. Stevenson’s voice. “Ok class, remember to enter the cafeteria through the door to the left. Once we arrive, you may sit wherever you’d like. And be sure to clean up your mess before leaving to go back to class.”



“Whoa...this cafeteria is MUCH bigger than the one at my old school”, Colbie told her classmates, a seemingly nice girl with long blonde hair named Sarah, and a boy named Cayle, as they sat down together at a table near the back of the cafeteria. Colbie began to unpack her lunch as her two new friends began eating.

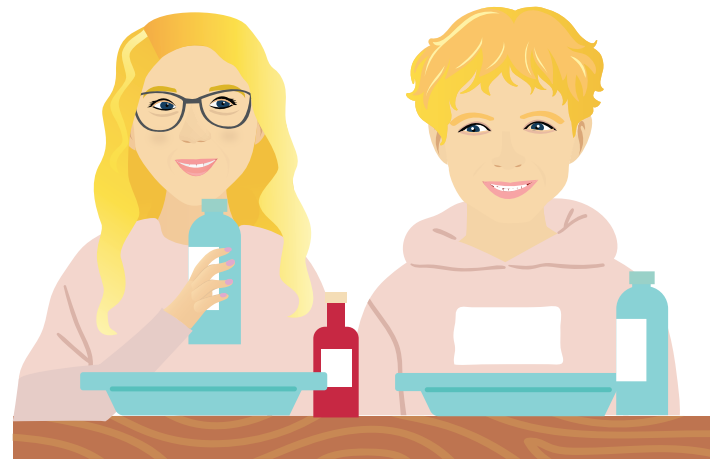


Colbie was starving! She wasn't used to waiting until almost 1:00 to eat lunch. She gobbled up her granola bar before opening her lo-pro coconut milk yogurt and a small pack of crackers. Then she took out her formula and took a sip. "What's that Colbie?", Sarah asked, looking at the bottle.



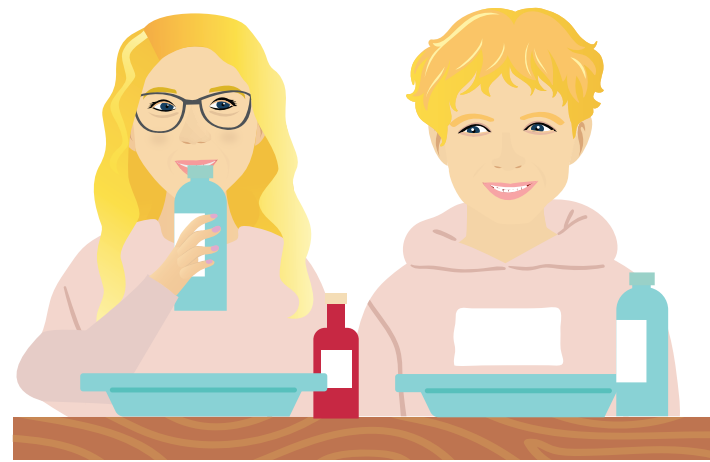
"Uhh..." Colbie paused for a second before blurting out "formula". "Formula?", asked Cayle, looking puzzled. "Yep." "Why do you have to drink formula?" "It's complicated...", replied Colbie, hoping that would end the conversation. "You mean like...like the stuff babies drink?" asked Sarah, looking at Colbie for a response. "No...not like that. It's a formula that gives me vitamins and other important stuff that my body needs. "You see...I...I..."", Colbie mumbled nervously, hoping the right words would come out. "I have to be on a special diet."

Sarah and Cayle sat quietly for a moment, before Cayle replied. “Oh yeah! My little brother is allergic to peanuts so he can’t eat them. Is it like that?” After noticing that neither Sarah nor Cayle were laughing or acting strangely, Colbie began to relax a bit.



“Not exactly,” responded Colbie. “I can’t have animal products, or things with a lot of protein.” “So....you’re vegan?”, asked Cayle, his head tilted to the side as if trying to figure out a puzzle. “Kind of, yes.”, Colbie nodded. “Cool”, said Cayle before turning to Sarah. “You gonna eat that? ” he asked, pointing to a cup of fruit that remained on her lunch tray. “No you can have it,” Sarah responded, handing over the cup.

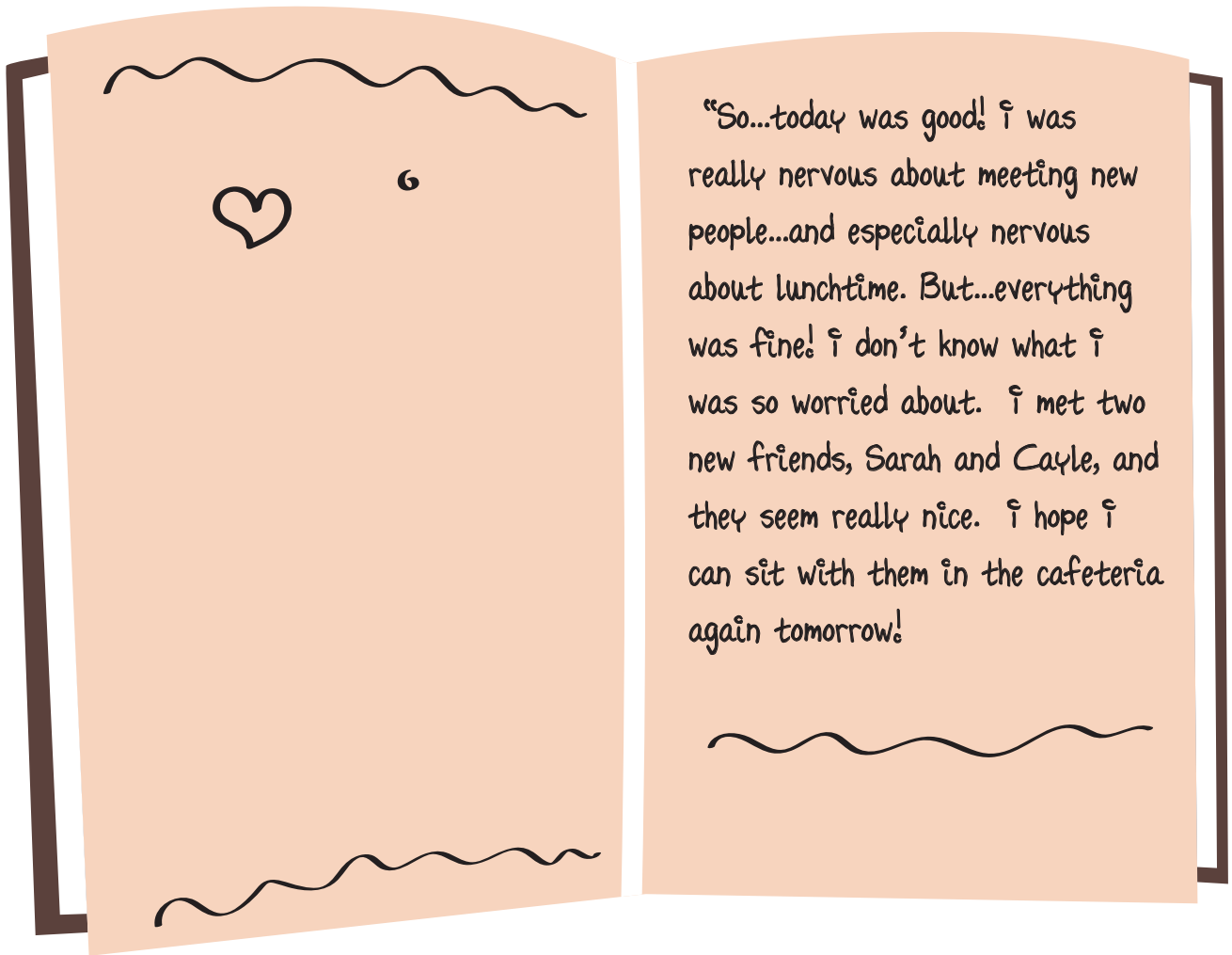
Feeling relieved that the conversation had turned away from herself, Colbie took a sigh of relief. “Maybe this won’t be so hard”, she thought, as she took one last sip of her formula.



“Well, how was school today?” her mom asked, as Colbie hopped into the car. “Good!”, Colbie exclaimed. “Did you meet any new friends?” “Yup...two kids from my class. Sarah and Cayle.” “I’m so glad. I knew you’d make new friends in no time,” her mom said back happily.



When they got home, Colbie put down her book bag and headed up to her room. She grabbed her journal and began to write.



"So...today was good! I was really nervous about meeting new people...and especially nervous about lunchtime. But...everything was fine! I don't know what I was so worried about. I met two new friends, Sarah and Cayle, and they seem really nice. I hope I can sit with them in the cafeteria again tomorrow!"

Colbie closed her journal and put it back on the bedside table. She thought for a second, and had an idea. Maybe planning out how she would explain her HCU to her new friends, if they asked her more questions tomorrow, would help her not to be so nervous. This way, she would have a plan and wouldn't have to stumble over her words so much. She thought about questions that people had asked her before. Then Colbie reached for her journal and flipped it back open.



Question: What does HCU mean? /
Why do you have to be on a special
diet?

Answer: It is complicated, but I have
a metabolic disorder where I can't
have protein. I will get sick if I have
too much protein.

Question: What is that formula for?
/ Is that milk?

Answer: It's something for my
diet...it gives me vitamins that I need.

Question: Will you grow out of it?

Answer: No, it'll be with me forever.

Question: Can you have just a bite?

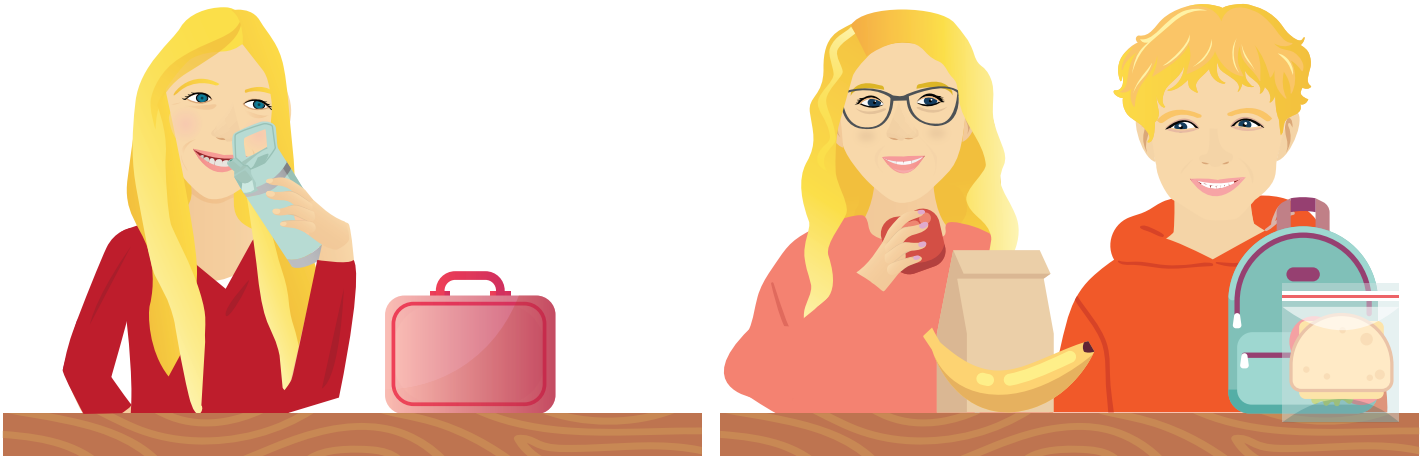
Answer: No...I have to stick to my
diet.

Question: Do you ever get sad that
you can't eat things that everyone
else can eat?

Answer: Not really. There are lots
of things that I can have.

“There”, said Colbie out loud, closing her journal. “That should help.”

The next day at lunch, Colbie was ready. She knew that the topic of her diet might come up again, and she felt confident, having prepared some ideas in her journal the night before. As Colbie unpacked her formula and took a sip from her straw, she decided to be brave. She looked at Sarah and then at Cayle. “Guys”, she started. “I have something called HCU. It stands for Homocystinuria. It is complicated, but it pretty much means that I have a metabolic disorder where I can’t have protein. I will get sick if I have too much protein.” Colbie paused, waiting for a response. “I’m sorry...”, Cayle responded. “It’s ok! I’m used to it”, Colbie answered back. Sarah didn’t say anything. She just smiled and continued eating her lunch.



That night, as Colbie finished up a little bit of math homework, she thought back to her conversation from the cafeteria. She wondered what her new friends thought about what she had told them. Colbie had never really been embarrassed about her HCU before, but being at a new school with new people, the last thing she wanted to feel was different.



Just then, Colbie heard a “Ding!” from her phone. It was a text message from Sarah. It read:

Hey Colbie, it's Sarah. I just wanted to say thank you for opening up to me today about your disorder. I didn't want to say anything earlier, but I have diabetes. I have to check my blood sugar a couple of times during the day and I have to watch what I eat, too. I don't usually tell people at school that because I'm embarrassed! But when you told me about your HCU, it gave me the courage...so thank you.

Colbie felt a huge sense of relief come over her. She typed a response, and hit send.

Thanks! :) I'll see you tomorrow!

That night, Colbie went to sleep feeling great. Not only had she already made new friends at her new school, but she also felt super proud of herself. “I AM brave...and I can do hard things...” she heard herself whisper... and she drifted off to sleep.



While the story is fictional, the characters are all real young people living with HCU. They live in different parts of the country, but were brought together by a shared condition - Homocystinuria. They have formed friendships that reach beyond the physical distance and provide a sense of support for each other. HCU is always a part of their daily lives, but it is only a small piece of who they are. Those who know the young people featured in this story describe them as:

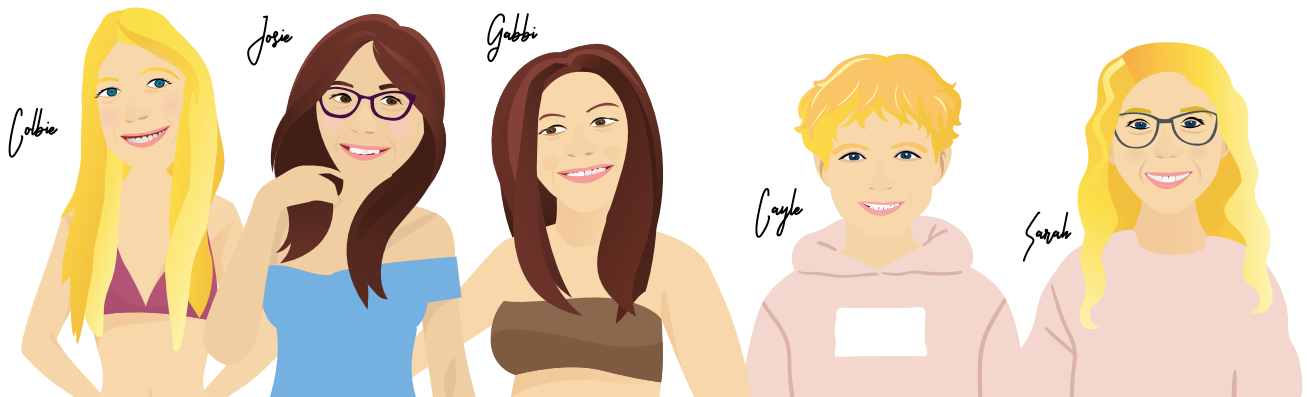
Colbie: “A fearless and outgoing lover of all animals, who has a heart of gold.”

Josie: “A prayerful daydreamer who reads and dances her way through the day and asks her parents questions they can’t answer.”

Gabbi: “A passionate artist, with a heart for helping others.”

Cayle: “An energetic sports-lover, whose kindness shines through to everyone he meets.”

Sarah: “A determined, athletic, lover of people who shines God’s light into the world each day.”



Classical Homocystinuria (Ho-mo-cys-tin-uria), or HCU, is a rare inherited metabolic condition. People with HCU cannot break down the amino acids methionine (me-thahy-uh-noon) and homocysteine (hō-mō-'si-stā-ēn) in their bodies. Methionine (Met) is found in most foods that contain protein. HCU is a severe medical condition that can be treated with a special HCU medical formula, a diet low in protein and Met, and some vitamins and other medicines.

To learn more about HCU, or to access helpful resources, visit:

www.hcunetworkamerica.org

www.hcunetworkaustralia.org.au

www.aeglea.com

