

# A DAY WITH NURSE JEN

An atypical-HUS Tale



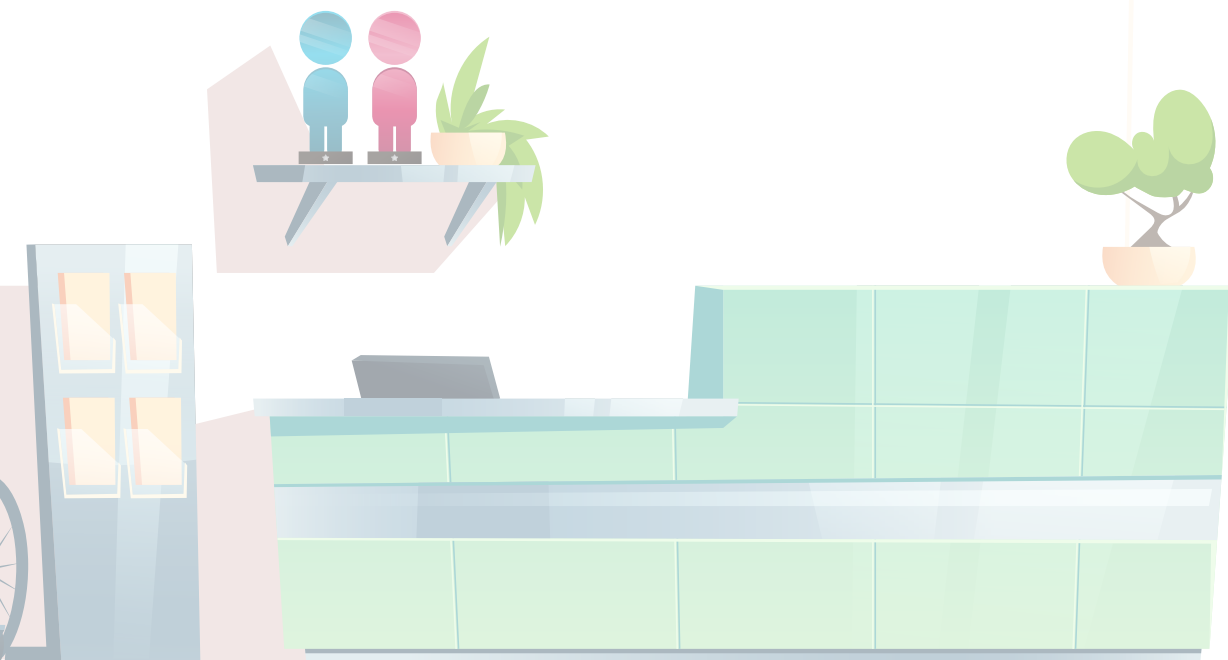
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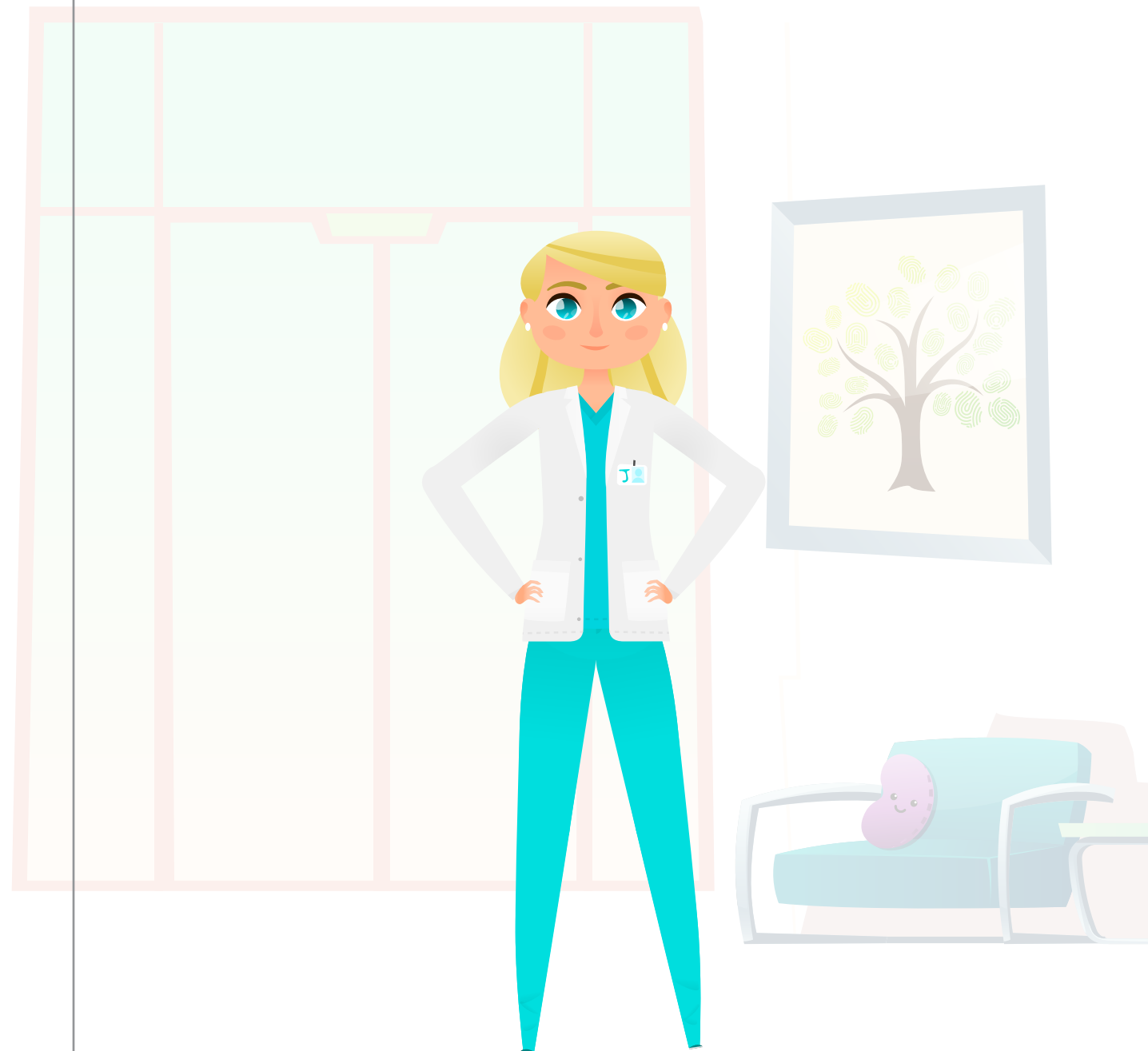
A Day with Nurse Jen: An atypical-HUS Tale  
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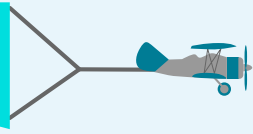
Book design by Snow Companies, LLC.



This book is inspired by Jennifer L., a nurse supporting the atypical-HUS community at the Pediatric Nephrology Center of Excellence, Atrium Health Levine Children's Hospital, in Charlotte, North Carolina. Her commitment to those living with atypical-HUS has inspired this fictional story.



## Special Thanks



### For helping make this project come to life:

Arpit G., Ben S., Bonnie P., Chris F., Jessica O., Kishan M., Rhonda D., Sarah H., Terri C., Tricia O., & Tyler G.



Jennifer L.

I want to dedicate this book to all my patients, who inspire me to work harder and give more daily. I've seen you grow through the years, and I am happy to be part of your lives and your families. A very special thank you to Emma and Ben for allowing me to

take a peek inside your window of life. Ben, you have taught me and so many others that atypical-HUS does not define you and it will not stop you from living out your dreams!

To my family and my kidney work family, I am dedicated to my work to make an impact on the lives affected by pediatric kidney disease and am grateful for your encouragement and support. A very special thank you to my mentors, Dr. Susan Massengill and Dr. Jack Weaver, for continuously teaching and inspiring me to be a better nurse and human.

Nurse Jen works in a very busy hospital. She helps people who have atypical Hemolytic Uremic Syndrome. That's a lot of words, so people like Nurse Jen call it atypical-HUS for short.

## Meet Emma

Nurse Jen starts today by meeting a young girl living with atypical-HUS, Emma. Emma is five years old and just learned that she has atypical-HUS. She and her parents recently arrived at the hospital and are still figuring out what atypical-HUS means.

Emma's mom thinks they should talk to Nurse Jen to learn more. "Remember how long it took to learn what you had? We were definitely worried. Maybe Nurse Jen can give us advice on what to do next."

Nurse Jen is familiar with how scary atypical-HUS can be. "How did you end up in the hospital?" she asks Emma. "Had you ever been here before?"

"No," Emma says. "I didn't know this could happen! When I was sick before, I just stayed home from school, and everything was fine."

"I thought I'd get better this time too. A couple of weeks ago, I got a cold, and it felt like all my other colds. But I didn't get better! I was coughing and sneezing a lot, and my tummy really hurt. I was so tired, and I stayed home from school. My mommy and daddy took me to the doctor. My doctor told me I had to see his doctor friends who could run some other tests.

"So we came here. My parents brought me in, and I saw all these doctors. They didn't know what was wrong with me either. They tested my blood and pee. They even took x-rays with a big machine."



Emma explains that it took a long time for the doctors to figure out what was wrong. "Finally, one of the doctors talked to my mommy. She knew what was wrong with me! She looked at all those tests and told me what I had."

"I'm so glad your doctor got the answer!" Nurse Jen says. "What you have is called atypical-HUS. That means you have a condition that you may need to take medicine for. Knowing you have it is the first step in making sure you're okay. Some people are sick for longer before they learn they have atypical-HUS and they need even more time to feel better."

*"But I don't know what atypical-HUS is,"*  
*Emma says. "I just know I felt sick."*

Nurse Jen helps explain. "Atypical-HUS means your body's defenses get carried away and start hurting you. You see, everyone has an immune system. It helps get rid of germs like a cold or the flu. That's why when you were sick before, you got better when you stayed home from school. Your immune system was taking care of everything.

"The complement system is an important part of the immune system. It's what fights off viruses and bacteria. If you don't have atypical-HUS, there are controls on your complement system to get it to slow down once all the germs are gone.

"But if you do have atypical-HUS, those controls don't always work so well. Your complement system keeps trying to fight germs that aren't there and hurts your body in the process. It's sort of like a runaway train. It moves down the tracks like it should, but it also keeps going past where people want to get off. That's what made you feel sick, even after your cold went away."

"What's next?" Emma asks.

"Don't worry; we have a plan!" Nurse Jen says.

"Now that your doctors found out that you have atypical-HUS, they can give you medicine that can help your body keep its complement system under control."

"Thank you!" Emma says. She is so glad her mom told her to talk to Nurse Jen. Emma feels less scared. Nurse Jen pulls a toy train out of her pocket and hands it to Emma.

*"Now how about you hold on to this," Nurse Jen tells Emma. "Take care of that train, just like we'll help you take care of your body!"*



## Meet Ben

A few hours later, Nurse Jen sits at her desk at the nurse's station. As she's busy working on her computer, 10-year-old Ben walks up to the counter.

*"Nurse Jen?" he asks in a quiet voice so that no one else could hear.*



Looking up, Nurse Jen recognizes Ben even though he's not in a hospital gown. He has been at the hospital for more than a week. "Hi, Ben. You look so much taller in your sneakers. Where's your mom?"

"Thanks." Ben smiles, feeling more confident. "She's still in the room packing up the rest of our stuff."

"That's right! I hear that you're going home today. Are you excited to see your brother and sisters?" Nurse Jen asks.

"Yeah," Ben responds without much enthusiasm. "I'm excited."

"You don't sound very excited," Nurse Jen says.

Feeling less confident, Ben looks down at his shoes again. "I am. I'm just not sure what will happen if I get sick again."

Nurse Jen smiles and comes around her desk to stand beside Ben. "Nobody knows the future. You just have to prepare for it the best you can and be ready to change your plan to meet each challenge as it happens."

"I know. But what happens if it's really bad? How will I know what to do?" Ben asks.

"If it's really bad, you'll come back to see me and your doctor," Nurse Jen answers. "You'll know you're feeling sick, and you'll tell your parents. It's not just you who has to manage your atypical-HUS. You have your parents and all the doctors and nurses here who can help you."

Ben protests, "But wouldn't it be better if I just stayed here and had doctors and nurses around me all the time?"

Nurse Jen considers Ben's question. "Won't you miss seeing your friends? Or school? Or riding your bike?"

"Yeah, but they can come and see me, and I can just do homework, like I've been doing," Ben answers.

Nurse Jen tries to explain in a different way. "Hospitals are for people who need help all through the day. Some people with atypical-HUS have to stay in the hospital longer. But in your case, doctors don't have to watch you every minute.



"You have atypical-HUS, but your doctors have a plan to help you keep feeling better. And for that plan, you don't need to be in the hospital all the time."

Ben thinks about what Nurse Jen is saying. He still looks concerned, but he knows that he wouldn't really be able to stay at the hospital. Nurse Jen continues, "You can play with your friends. You can go back to school and go out to the movies with your family. You'll just come in for medicine whenever your doctor tells you to so you can keep your atypical-HUS in check."

"But how will I know what to do if something bad happens?" Ben asks again in a different way, hoping for a different answer.

*"Your parents, your doctor, and I are there to keep an eye on you and monitor your complement system. But soon, you'll know what to look for too. Just do your best to stay healthy and talk to your doctor."*

Ben feels a lot better as he takes in everything that Nurse Jen just said.

He thinks carefully for a moment, then he says, "Thank you, Nurse Jen. I better go help my mom get everything together. Bye."

"Goodbye, Ben. I'll see you when you come in next time." Nurse Jen waves as Ben races down the hall.

Nurse Jen makes a note to give Ben and his mom some brochures about his medicine and the infusion center where many people, including some with atypical-HUS, go to get their medicine.

Later that afternoon, Nurse Jen heads to the infusion center where she works part-time.

## Meet Nicole

Today, Nurse Jen is excited to speak with a patient she knows very well, Nicole. Nicole is 14 and has been diagnosed with atypical-HUS for a while. Over time, she has learned a lot about atypical-HUS and what getting medicine is like.

After spending the day with Emma and Ben, Nurse Jen has been thinking about how hard it can be to start your journey with atypical-HUS. She asks Nicole to tell her what she's learned about getting her infusions so Nurse Jen can help other kids in the same situation.

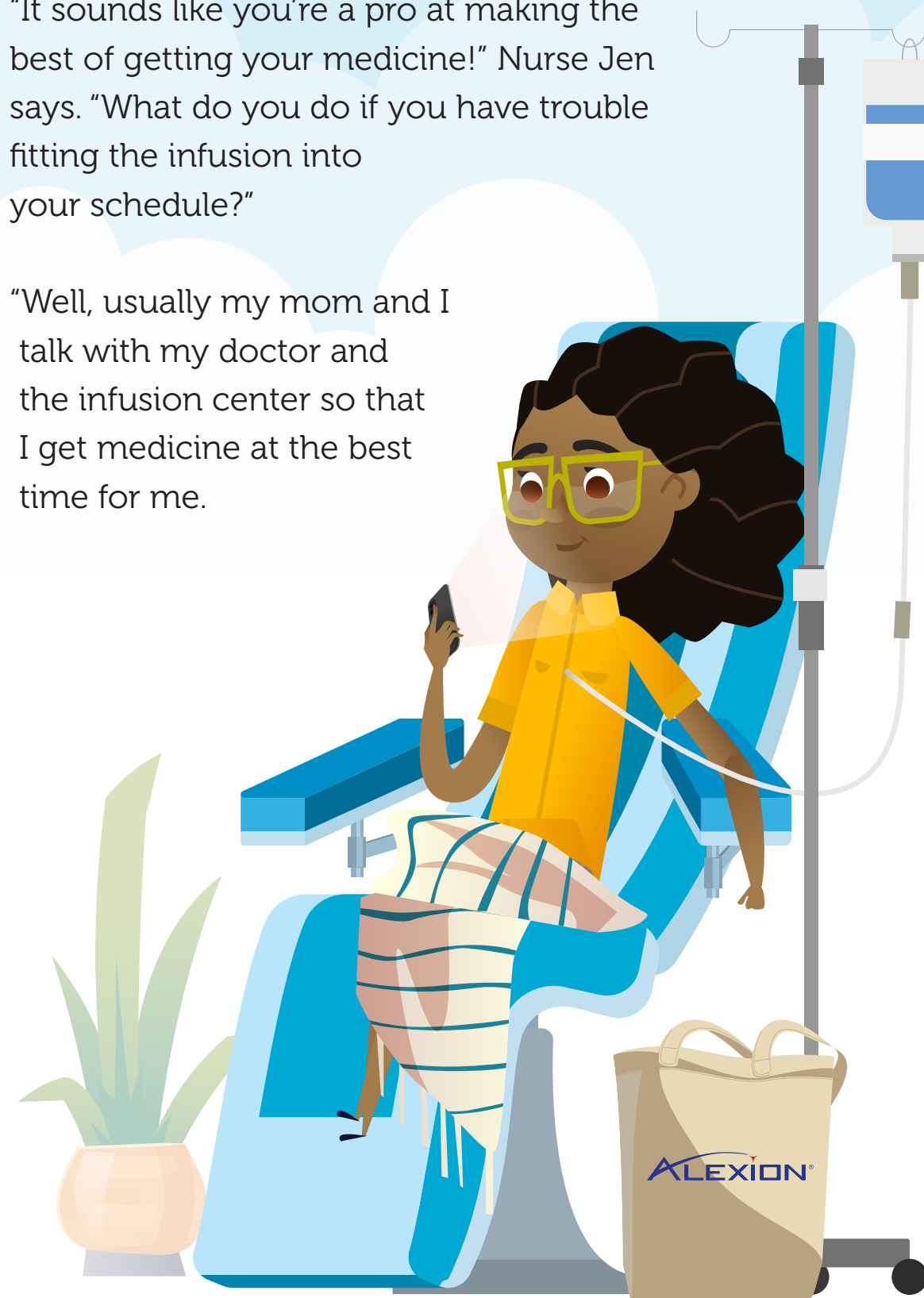
"I don't mind getting my infusions now," Nicole says. "I was a bit nervous when I first started. I didn't like having to get them by needle. Then I got a port, and that made getting medicine easier for me. I do still have to sit in a chair for a bit. But everyone here makes sure I'm comfortable.

"Sometimes I sit and talk with you or one of the other infusion nurses. In the beginning, that helped calm me down a lot. But now, if you're busy, I just read a book or watch some TV on my tablet. I know to bring a blanket with me too so I can relax. Sometimes this is when I actually get to do stuff I want, like spending time with my friends if they visit.

"I've even become friends with the other kids who have atypical-HUS and get their infusions when I do. I call them my 'kidney family.' Plus, my mom doesn't make me do homework when I'm getting my infusion!"

"It sounds like you're a pro at making the best of getting your medicine!" Nurse Jen says. "What do you do if you have trouble fitting the infusion into your schedule?"

"Well, usually my mom and I talk with my doctor and the infusion center so that I get medicine at the best time for me.



“But if I’m traveling somewhere, like if I’m going on vacation or to drama camp, we reach out to my patient support program. They help me get infusions at a different location.”

Nurse Jen is very proud that Nicole is doing all she can to stay on top of getting her medicine. It’s a big step to go from being diagnosed to making atypical-HUS just another part of your life. “How is everything else going?” Nurse Jen asks Nicole. “You’ve just started high school, and it can be hard to manage atypical-HUS and a new stage in your life.”

*“Well,” Nicole says, “I feel pretty comfortable getting medicine for my atypical-HUS.”*

She pauses and bites her lip. “But I don’t know if I can do everything I want to. I’m thinking of trying out for the fall musical, but is it safe to do that while having atypical-HUS?”



"I still want to hang out with my friends and do afterschool activities like them. But I'm not sure if I can and stay healthy." Nicole frowns. Balancing her atypical-HUS and her first year of high school has been a struggle.

Nurse Jen tells her, "There are lots of activities people with atypical-HUS can enjoy, and your friends will understand if you may have to sit one or two things out. Just keep up with what you're doing and get your infusions on time. Oh, and make sure you check with your doctor before joining any clubs or starting a new activity. She'll know best if something is safe for you to do.

"Atypical-HUS is part of your life, but it doesn't always have to be the focus of it. I'm sure we'll see you shining on that stage!"

Nicole gives Nurse Jen a big smile. She is confident about managing her atypical-HUS, and Nurse Jen has made her feel even better about the future.

Her infusion is over. During the hour after infusion, Nurse Jen checks to make sure she is good to go. Then, Nicole calls her dad to pick her up. She's excited to tell him everything Nurse Jen said about enjoying life with atypical-HUS!

Nurse Jen watches as Nicole walks out the door and gets into her dad's car.

A voice from behind her asks, "Are you ready?"

Nurse Jen turns to see the infusion nurse setting up a new infusion bag next to the reclining chair. She stands up straighter.

*"Yes. I'm ready."*



That's right. Nurse Jen has atypical-HUS too! Now it's her turn to get medicine. Nurse Jen rolls up her sleeve as she sits down in the chair. It is the end of a long day, but a good day because she talked to three amazing kids all dealing with atypical-HUS at very different stages of their journeys.

The infusion nurse says, "Okay, let's get started," just before she inserts the needle for Nurse Jen's infusion.

*Nurse Jen settles into the chair, goes over tomorrow's schedule in her head, and thinks about everyone she's seen today.*



Emma is just starting her journey. She and her parents have a lot to learn about how Emma's immune system works. They know now that with atypical-HUS, her immune system can be like a runaway train. And they will work with her doctors to help keep Emma's body's defenses from getting carried away and hurting her.

"How are you feeling?" the infusion nurse asks, interrupting Nurse Jen's thoughts.

"A-okay," Nurse Jen replies, surprised by how much time had already passed.

Ben is doing well with his treatment and is heading home. He has learned so much about what to do in case his immune system gets off track. He still has training wheels on his atypical-HUS plan, but his doctors and family are there to help.



"Your infusion is done," the infusion nurse says as she takes the needle out. "You know we'll want to monitor you for a while, so I'll be checking on you soon."

"No problem," Nurse Jen answers. "I'll wait here until you say I can go." She likes having the time to think.



Nicole has come so far in her journey. Just a year ago, she was scared and nervous too. But today, she has these infusions figured out. Now she can audition for that musical and light up the stage.

"We're all done here," the infusion nurse says. "Are you still doing okay?"

*"Absolutely. Not every day can be a good day, but there is good in every day. And today has been a great day!"*



“This book highlights the strength and resilience of patients facing atypical-HUS, as well as the amazing nurses and staff who make it possible to improve their lives.” – Dr. Jack Weaver

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