

SUPER SEVEN

A STORY FOR RARES



NATIONAL HEMOPHILIA FOUNDATION
for all bleeding disorders

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A STORY FOR RARES

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Super Seven – A Story for Rares

People with bleeding disorders and their family members are the center of the work of the National Hemophilia Foundation. We support research that has a measurable impact on people’s lives; deliver education that helps people with bleeding disorders and their family members thrive; and advocate for policies at the state and local level that protects access to healthcare.

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**This book is dedicated to all people
with rare bleeding disorders.**

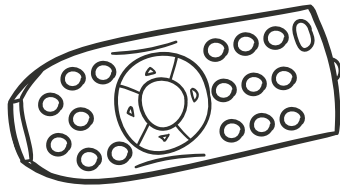
Foreword

What is a rare bleeding disorder?

Most bleeding disorders are rare, but some are more rare than others. When a bleeding disorder is very rare, that means that only a very few people have it. Sometimes, a bleeding disorder can be so rare that only one in a million people have it! NHF created this book for boys and girls with very rare bleeding disorders.

There are many very rare bleeding disorders, also called “rare factor deficiencies.” Factor I (1), II (2), V (5), VII (7), X (10) and XIII (13) deficiencies are all rare bleeding disorders. There are also other rare bleeding disorders, like Bernard-Soulier syndrome, Glanzmann’s thrombasthenia, or platelet storage pool disease. Each of these bleeding disorders affects a person differently. Some may have to take medication, like Tanner does in the story. Some don’t. Some may have nosebleeds, like Tanner does. And some people may have very few symptoms at all.

But everyone who has a rare bleeding disorder is important. And everyone who has any type of bleeding disorder, whether it’s a very rare bleeding disorder, or less rare one like hemophilia or von Willebrand disease can get to know Tanner’s friends and family. You may find that you all have a lot in common!



Chapter 1

“I’m open, I’m open!” I yelled, racing down the basketball court, waving my left arm.

“Me. Luis! Me!” yelled Marco, one of our forwards. He’d made it all the way down the court. Now he was under the basket, bouncing in place.

“Luis! Eleven seconds!” cried our coach from the sidelines. “Pass!”

Our middle-school team, the Hornets, were playing against the Spartans in the semi-finals of the district tournament. The winner would play in the championships on Friday.

Luis caught the rebound off the backboard, pivoted, and followed us toward the basket. But now he was trapped ... standing still. Surrounded by two Spartans. Their tall bodies, waving arms, and lunging hands.

It was the fourth and final quarter of the game, and we were tied. Tied!

The crowd in the Spartan’s school gym was roaring.

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Most were Spartan fans but some of our fans had come as well.

“Luis, ten seconds!” yelled Coach Velasco.

All our players were standing, shouting.

“Nine seconds ... eight ...” yelled the crowd.

Luis couldn’t advance from there. He had to shoot or pass. I waved again to show I was still open. So did Marco.

Another Spartan covered Marco. He was massive. It looked like he was in the ninth grade, though he couldn’t be. Only players in grades six through eight could play.

Most of the guys on our team were in the eighth grade except for the four of us in seventh grade who had practiced like crazy to make the team. Me? Well, Dad had put up a hoop in our driveway last year. I spent every free minute playing one-on-one with my friends or even one of my parents. Whenever I have an injury, which happens more than I’d like, I’d practice shooting. Shooting from under the basket, from the foul line, and beyond the three-point line.

“Seven, six ...”

Luis looked at the hoop. Would he shoot, try to win the game in the last seconds or pass?

“Five, four ...”

Luis looked at Marco, looked at me, gave a tiny nod—was he going to pass to me? My heart pounded. It would be my big chance! My chance to win the game and take us to the finals!

Then suddenly, surprising everyone, I’m sure, Luis drilled the ball from his chest at Marco.

Who caught it and spun on a dime.

“Three, two ...”

Lifted off, and ...

“One.”

... shot the ball!

The basketball flew through the air as the buzzer sounded. But because the ball was airborne, a basket would count.

The crowd yelled. I held my breath.

And the ball went through the hoop, swish!

We all started cheering, our fans in the crowd too. We’d done it! We won the game.

We’d advance to the championships.

No, Luis hadn’t passed to me. But he thought about it. I knew it. And it didn’t matter anyway. I was a great shooter and the championship game was coming in four days, and I’d have the chance there to score. To win the big one for the Hornets!

Go Hornets!



When I got home I told Mom, Dad, and my seven-year-old sister Victoria all about the game over dinner. The game had been at the Spartans’ school. Some parents had volunteered to drive a bunch of us there and home again. Mom and Dad explained again that they were sorry they had to work and miss it.

“But we’ll be there on Friday, for sure.” Mom promised.

Dad high-fived me across the table.

Victoria rolled her eyes a bit but said she wanted to come too.

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She wasn't so nice when Mom and Dad agreed we could watch a TV show after dinner and she insisted we watch a show she wanted.

"No way," I argued. "I should choose because my team just won a big game."

"You only got 6 points," she pointed out.

That made me mad.

"Well, that's six more than you got," I snapped. "Plus on Friday, you just watch. I'll get twelve, maybe even twenty in the finals."

"Well, you can choose the show on Friday, then," she said. She stuck out her tongue.

"Sorry. Wrong," I said. "We are not watching this stupid kids' show."

Victoria and I were both sitting on each end of the couch. I jumped up from my end to reach for the remote on the coffee table, and she leaped up from her end to grab it too. The next thing I knew, I was tripping over the table leg. When I tried to catch myself, my ankle rolled under me, and I hit the floor.

"Ow," I said.

I grabbed my ankle.

"Victoria!" I yelled. "Why did you do that?"

She looked back at me, wide-eyed. "Sorry," she whispered and tried to hand me the remote.

But I ignored her.

"Ow," I said again, and tears came to my eyes. Not because it hurt so much. But because of what it might mean.





Chapter 2

The balled-up pair of socks sailed through the air, thumped against my bedroom door, and dropped through the mini-basketball net on the back of the door. “Tanner gets three!” I shouted, raising my arms in the air.

The door opened, Mom looked at the socks on the floor, up at me, and quirked an eyebrow.

“Hey, LeBron,” she said. “I’m off to work. Come down for breakfast or you’ll be late. And still no biking for you today. Not until your ankle’s completely healed. If you hurry, Dad will drop you at school before he drops Victoria.” She picked up the socks and tossed them back at me. “Can you at least try to aim for the laundry hamper?”

“That’s Super Seven to you, Mom,” I told her, grinning. “And the hamper isn’t high enough.”

She glanced back at me, smiling. “You’re getting too tall,” she said.

“No such thing,” I replied, tossing the socks in the hamper. Day four since the semi-finals. Since my little ankle twist.

I grabbed a clean pair of socks and put them on, first the right, then—I winced as I pulled on the left one. My ankle still ached.

Why was my blood so useless? Why was Victoria so clumsy?

I pulled off the sock. Grabbed the elastic bandage I'd taken off last night and tossed on my desk. I slipped it over my ankle and pulled the sock back on it. Then I swept my homework from my desk into my backpack and grabbed my gym bag.

By the time I got downstairs, Mom was heading out the front door, calling, "Bye all. See you at the game!"

Dad was in the kitchen, sipping coffee and making our lunches at the counter. Victoria sat at the table, slurping up cereal.

I scowled at her, snatched away the cereal box and poured some into my bowl.

"The game is at six," I reminded Dad. "Will Mom remember?"

"She knows, and I know, we wouldn't miss it for the world," Dad said, with a reassuring grin.

"It's the first time we've ever been in the finals," I told him. He knew that also, but I liked saying it out loud.

"You all had a great season," he said. He took a quick sip of coffee and continued packing my lunch, his back to us. "We're really proud of you. All three of us."

I looked at Victoria. She picked up her bowl and drank from it, hiding her eyes.

"Thanks, Dad," I said, continuing to glare at my sister.

"Tanner...how's your ankle this morning?" Dad asked.

I didn't take my eyes from Victoria. "Fine, Dad."

Victoria set her bowl down, her eyes welling up with tears as she left the room.

“Be ready to go in fifteen minutes, honey.” he called over his shoulder to her.

He sealed her brown paper lunch bag and turned.

“Tanner,” Dad repeated, firmly, looking me in the eye. “It’s only been a few days since you tripped.”

I took a mouthful of cereal and crunched on it. Dad waited.

I chewed and swallowed. I took a deep breath. “My ankle still hurts,” I admitted.

He nodded. “The bleed only happened four days ago,” he reminded me.

“I know,” I mumbled. Thanks to Victoria.

I shoveled in another spoonful of cereal.

“Tanner,” Dad said. “I think you need a plan for the day. I think your plan should be: take your medicine, go to school, and tell Coach Velasco about the bleed. He’ll understand why you can’t play today. Does that sound good?”

I thought about it. I didn’t want to tell Coach anything. Yeah, my ankle still hurts now, but the game wasn’t for another eight hours. If I told Coach now, he’d bench me for the game for sure and ... well, I hadn’t quite decided whether I’d play today or not.

But Dad didn’t have to know that. He’d only worry.

“Yeah, I guess. Okay.”

“Okay.” Dad took a sip of coffee. “And no matter what happens, you’ll suit up and join your team on the floor after school, right? Mom, Victoria, and I will be there to cheer you all on.”

I tried to smile back. But, man... not playing in our middle school championship game after working hard all last year and this season to get there?

It just didn't seem fair.



Chapter 3

My parents told me that having a bleeding disorder is really rare. Rarer than being double-jointed, left-handed or having red hair. Rarer than having two different-colored eyes. I've never met anyone with two different colored eyes (cats don't count). I've never met anyone else with a bleeding disorder, although I know they're out there. Bleeding disorders are usually passed down from parents to kids, but not always because it was a big surprise when I was born and the doctors told my parents I had one.

It means my blood doesn't clot that well. When a kid who doesn't have a bleeding disorder bangs an arm into a locker or slips off a curb and twists an ankle a tiny bit, they say "Ow," and forget about it. Not me though. I wind up with huge bruises. Or, my ankle starts to bleed on the inside. And instead of bleeding for just a little bit and then stopping, mine just keeps going. Then the joint is full of blood and hurts.

Which is what happened a few days ago.

Because of Victoria.

Dad cleared away the breakfast dishes. “Okay, we need to get moving. Tanner,” he said. “Get your super juice supplies.”

Mom and Dad call my medicine “super juice” even now. They started calling it that when I was really little when it was hard to get me to sit still when they gave me my medicine. The needle hurts a bit and back then, it bothered me a lot more. Anyway, I don’t mind that they sometimes forget and call it my “super juice” once in a while—as long as they never, ever, ever say it in front of anyone else.

I reached for the plastic three-drawer organizer where we keep all my bleeding disorder infusion supplies. I have to inject my medicine into a vein in my arm – it’s called “infusing.” That’s why the organizer looks like something you’d see in a doctor’s office. Boxes of latex gloves, butterfly needles, plastic tubes, a couple of tourniquets, alcohol wipes, and plastic tubs to put the used needles in.

I opened one drawer and then another, taking out a syringe, a butterfly needle, my favorite dark blue tourniquet, a couple of alcohol swabs, a Band-Aid, a pair of gloves, and my infusion mat.

I grabbed a small box of my “super juice” from the fridge. The medicine is actually blood clotting factor—the stuff my body is missing. I normally only infuse every Monday, Wednesday, and Friday to help prevent bleeds from happening. But because I have an active bleed from when I twisted my ankle, I needed one every day for a bit to help heal it.

I washed my hands at the sink and wiped the mat down with an alcohol swab.

I had to pay attention to what I was doing so I didn’t forget a step, but it was so routine, it was difficult to focus.



Plus, the game ...

As I slipped on the latex gloves, my mind kept flitting around. Play? Not play?

My stomach clenched. I hated that I even had to make this choice. Stupid Victoria. Stupid bleed. Stupid disorder. Stupid.

“Okay, I’m ready,” I told Dad.

He glanced over and looked at the setup. “Nice,” he said.

He watched while I put on the tourniquet, tightening it around my upper arm. The dark blue one was my favorite because it didn’t pinch. I clenched my fist—that made my veins easier to see—and lay my arm flat on the table with my wrist facing up.

I picked up the butterfly needle, inserted it into my vein like I had been taught—“like an airplane lands”—slowly plunged the factor into my body, drew out the needle and threw it into the plastic tub. I stuck a band-aid over the tiny pinprick.

“Factor, do your stuff,” I said.



Chapter 4

“Hey, Tanner!” Jax was waiting for me beside the bike rack. “Hey, Mr. Johnson! Hey, Vicky!” Jax waved to my Dad and sister as they pulled away from the curb. He was heading over to drop Victoria at the elementary school now.

My family and Jax’s family were pretty close. Jax has been my best friend since Mom, Dad, Victoria, and I moved here two years ago. We lived in a town a few hours from here but my parents thought it was best if we came to the city to be closer to a major hospital. Yup, because of me.

I remember Victoria didn’t want to move. She cried when she said goodbye to her friends. I wasn’t crazy about the idea either, but if we hadn’t moved here, Victoria never would have met her new best friends Maura and Riley, and I never would have met Jax. So there’s that.

On my first day of sixth grade, Jax sat behind me in class. We were arranged alphabetically by last names, and he and I are Johnson and Johnston. A half-hour later, he tapped my shoulder and when I turned around, he had a pencil

sticking out of each ear and nostril. “Do you have a pencil I could borrow?” he asked.

I laughed and the teacher yelled at both of us. That sealed the deal.

“Hey, Jax,” I said, as we fist-bumped.

The bell rang and we hurried toward the main doors.

“So are you ready to kick some butt on the court later?” he asked.

“You know I am,” I said, which wasn’t really a lie. I was ready psychologically. Emotionally. Just hadn’t decided if I was physically ready.

“You and me both,” said Jax. He isn’t actually on the basketball team, and he won’t actually be on the court during the championship game. He plays trumpet in the band, and they’ll be sitting in the bleachers, playing during half time. It’ll be noisy and fun, for sure.

Jax says he’s the power forward of the band, and I’m not exactly sure what that means but I think it means he’s good.

Coach Velasco was standing by the school doors. He teaches social studies and we’re supposed to call him Mr. Velasco in class. But we can tell he doesn’t mind if we call him Coach by accident. He nodded to us, and I swallowed nervously.

“Hey, seven!” Coach called. He always calls the guys on the team by our numbers. “Ready to show those Cougars who can’t be messed with?”

“I..am.” I said, which sounded super dumb. Coach didn’t notice though. The bell rang again.



“See you in the gym at 3:45 sharp, seven.” he called after us.
“We’re counting on you.”

I nodded and slipped past him.

“What’s up?” Jax asked as we hurried down the hallway, noticing my expression.

I shrugged.



Chapter 5

“These teachers need to get their act together.” I told Jax. I pulled open my locker door to grab my lunch. “Giving a math test on a Friday? Before the most important game the Hornets ever play? That should be illegal.”

Jax was chewing on a pen. He took it out of his mouth to ask, “How did you do?”

I shrugged. “Okay, I guess. Not too bad. You?”

“Eh.” Jax stuck the pen back in his mouth. “I don’t see why we need fractions.”

Math isn’t Jax’s best subject.

I shoved the papers, notebooks, textbooks, and other odds and ends back into my locker, quickly slammed the door shut, and replaced the lock.

“Fractions are totally over-rated.” Jax continued.

We thought about eating outside but it was too cold. So we headed downstairs to the—our English teacher Ms. Poole would like this word—aromatic cafeteria.

We walked past a group of eighth grade guys standing

around with a bunch of girls.

“Seven,” said Marco, with a nod in my direction.

“Hey, twenty-two.” I replied.

We went down the stairwell and came out in the basement.

“Yup, smelling it already.” I said, and Jax laughed.

A bunch of the guys on our team were goofing around down at the far end. One had a basketball and was bouncing it against the wall, which is totally against the school rules. Some of the players on the girls’ team were there too. They were laughing and body-checking some of the guys.

One guy fell, and two girls grabbed his hands to hoist him up. He got to his feet, brushed off his hands, and kept bouncing around, like it was nothing.

And to him, it *was* nothing.

Jax and I walked toward the cafeteria door. The girls laughed and one hip-checked the dude again, and he didn’t care.

My throat got tight, and I swallowed hard.

“And what’s so great about total accuracy?” Jax was saying. “Who needs to know if something is seven-elevenths or twenty-four yards, two feet, and forty-nine and a half inches? I mean, really. Why can’t we just...round up or down?” Jax suggested. “It’d be simpler.”

It was a good distraction. So I thought about that for a minute.

“So anyone who is, like, five foot six automatically gets rounded up to six feet tall?” I asked. Yes, I was five foot six.

“Sure,” Jax said. “Yeah.”

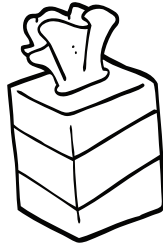
“And anyone who is, like, five foot four automatically gets rounded down to five feet tall?” I finished, with a sideways

glance at my buddy.

Jax, who was two inches shorter than me, made a face and swung his lunch bag at me.

“Funny, dude.” he said. “Very funny. Listen, forget the career as a comedian. Stick to basketball.”

I laughed and so did he, and we headed into the aromatic cafeteria, and things were good for a bit.



Chapter 6

At the end of the day, we filed into Ms. Poole's classroom. English was our last class. Jax took his seat behind me.

Was I feeling bad that I hadn't mentioned to Jax the possibility that I might not play in the game this afternoon?

Yes.

Did I think he might be able to help me decide what to do if I confided in him?

Yes.

As Ms. Poole wrote vocabulary words on the whiteboard, I carefully rotated my left foot. It didn't move entirely freely. And it ached a little. It always did for a while after I'd had a bleed into a joint. But it wasn't bad, actually. Not too bad.

Maybe it would be fine. Maybe I could play this afternoon. Even for two quarters. Or one.

I rotated it once more, being a little more aggressive. The little ache sharpened into a spike. I tried to push down my disappointment.

"Okay, everyone should know these words, which will

be on next week's quiz," Ms. Poole said. "Let's do a speed round." She pointed at the first word, vigorous. "Hands up if you know."

A forest of hands shot into the air.

So, why hadn't I talked about it with Jax?

Maybe because he was smart and although he could be goofy and do silly things, and he really knew how much I wanted to play in the championship game. He was also my very best friend and I knew what he'd say.

Because yes, Jax knows I have a bleeding disorder. I had to tell him soon after we moved here and became close friends. My parents insisted. They said if I was going to spend any amount of time at Jax's house, he and his parents all had to know. Because if I got a bleed while I was there—and it was likely I would at some point—they'd need to know what it was, what it meant, and how to help me out with it.

Jax has been great about keeping my disorder to himself. Once, he asked me why I didn't tell anyone else at our school about it.

I paused. I'd never told my parents. But this was Jax. "When I was in second grade I told a few kids at my old school about my bleeding disorder," I said. "They made faces and told some other kids. A bunch of them began teasing me about it and it kept on for years. I became Bleeder Boy."

"Not cool." Jax said, frowning angrily, and never brought it up again.

But he still doesn't really know what it's like. To feel like I have to be careful in a way no one else does. To be different from everyone else.

"Great, let's keep this going," Ms. Poole was saying. She

pointed to a word on the board. Stubborn.

Three or four hands waved.

Anyway, yeah. Jax still doesn't really know what it's like to have a rare bleeding disorder, but he kind of gets it. Like, he knows sometimes I just can't do some things. Not because my parents say I can't, or the teacher says I can't. But because my body won't let me. It would end up hurting or even harm my body later on.

And so that's why I didn't tell him how my ankle was feeling today.

I didn't want to hear his advice.

"And another," Ms. Poole said, pointing to another word on the board. I raised my hand.

"Tanner." she said.

"Unique." I read. "It means one-of-kind." Like me. Like the way I feel too often, unfortunately.

"Good," Mrs. Poole said.

I smiled, then felt something warm running down my lip. For a moment I didn't realize what was happening until I saw a drop of blood hit my desk. I clamped my hand over my face, pinching the bridge of my nose.

Oh, great.

And yep, next to me, Cassandra drew in her breath. "Ooh, gross, Tanner. You're bleeding everywhere. Stop it."

You'd think this was the first time she'd ever seen blood. Seriously. This wasn't great, but ...

"Tanner, you're disgusting. Don't get any on me." Cassandra fluttered her hands at me while shifting her chair away. "That's what happens to my brother all the time because he picks his nose."



The class laughed. Sort of at her but mostly at me. Just like they used to do at my elementary school. Because, yeah, getting nosebleeds in class isn't new to me. It's one of the charming parts of having a bleeding disorder. It doesn't hurt or anything, but they can take a long time to stop.

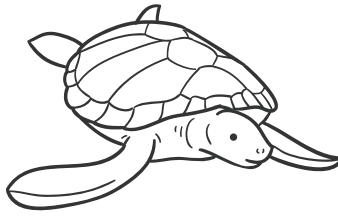
Ms. Poole turned and walked over to my desk. "Nosebleed?" she asked me.

When Cassandra responded, "Yes!" and nodded dramatically, Ms. Poole frowned at her.

She moved to stand between Cassandra and me and lifted her eyebrows. "Tanner?"

"Yeah, Nosebleed." I muttered, my hand still clamped over my face.

She nodded. "Straight there." she said and headed back to the board. "Now come on, people. Some of these are repeats. Sarah! Go for it."



Chapter 7

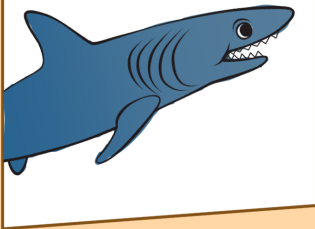
When I walked into the nurse’s office, she took one look at me, grabbed a box of tissues, and pulled out a huge handful. “Tanner! My favorite nose-bleeder.”

I laughed a little.

Miss Johnette gently pulled my hand away from my face and covered my nose with a wad of tissues. I knew the drill. I squeezed the bridge of my nose again and tipped my head forward.

“Okay, let’s get you sitting down.” She steered me backwards a few steps until I felt a chair hit the back of my knees. “Sit here.”

I like Miss Johnette. When I started school here last year, Mom and I had a meeting with her and Mom explained my bleeding disorder. We have to do this with people sometimes, even with nurses – explain what my bleeding disorder is and what to do in case I get a bleed. Usually Mom or Dad do all the talking, but when we met with Miss Johnette, after Mom was done talking, Miss Johnette had turned to me. “So, Tanner,”



PLAYING IT SAFE
NEWS RELEASE: SPORTS AND RECREATION

Why People with Bleeding Disorders Should Participate in Physical Activity

KEY TAKEAWAYS:

- ✓** People with bleeding disorders should participate in physical activity.
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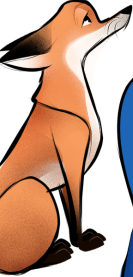
CONTRAINDICATIONS:

- Severe osteoporosis
- Severe heart disease
- High blood pressure
- Diabetes
- Glaucoma
- Obesity
- Other medical conditions

ABOUT THE RATINGS:

Activity	Low Risk	Medium Risk	High Risk
Swimming	Green	Yellow	Red
Walking	Green	Yellow	Red
Running	Green	Yellow	Red
Cycling	Green	Yellow	Red
Weightlifting	Green	Yellow	Red
Cardio	Green	Yellow	Red
Yoga	Green	Yellow	Red
Strength Training	Green	Yellow	Red
Team Sports	Green	Yellow	Red
Individual Sports	Green	Yellow	Red
Recreational Activities	Green	Yellow	Red
Professional Sports	Green	Yellow	Red
Extreme Sports	Green	Yellow	Red
Adventure Sports	Green	Yellow	Red
Water Sports	Green	Yellow	Red
Winter Sports	Green	Yellow	Red
Summer Sports	Green	Yellow	Red
Year-round Sports	Green	Yellow	Red

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she said. “What does a bleed feel like?”

“Kind of...tingly.”

“Like pins and needles? Like when your foot falls asleep?”

“No...more like...there’s a lot of soda in there that can’t get out, but it’s hot soda.”

She nodded, looking impressed. “Okay. Well, that sounds like you’ll know when that’s happening and you’ll be able to come and see me the minute you feel that, right?”

I liked that she asked me questions about how a bleed felt, instead of my mom.

As it turned out, I wind up seeing her quite a bit. More for nosebleeds than for the kinds of bleeds you can’t see, like what’s happened with my ankle. I’ve had a few of those in school though—this is my first one this fall but I had at least one last year. Miss Johnette had to call my dad. He told her I could take the spare dose of medicine Miss Johnette keeps for me in her office. I infused in front of her. She said she was impressed.

Luckily, even though I don’t ever like why I’m there, I like her office. She has pictures of sick animals like lizards and birds framed all over the walls. This afternoon, when I tipped my head forward, I looked into the face of some sort of giant turtle. “Do you need to call your dad or mom?” Miss Johnette asked.

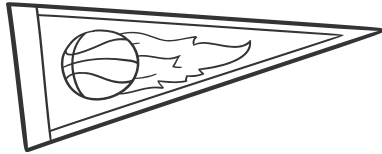
“No,” I mumbled behind my cloud of tissues.

“When was the last time you took your medicine?” She stood next to me.

“This morning,” I said. “So maybe the nosebleed won’t last that long?” I added hopefully.

“Hmm. We’ll see.” She studied me for a moment, then gave me a few more tissues. “Keep that head forward and just relax.”

I exhaled, propped my elbows on my knees, and closed my eyes. I wondered where that turtle lived.



Chapter 8

I heard footsteps, and a voice say, “Miss Johnette? I... um...need to talk to you.”

I opened my eyes. A girl that I sort of recognized was standing in the doorway. She had a plastic bag dangling from one hand.

Abigail looked over at me and I closed my eyes again. I probably recognized her from one of the other seventh grade classes. There are some kids in that class that I’ve never met. Girls, mostly.

Miss Johnette and Abigail moved behind the railed curtain in the corner of her office and were talking in low voices so I couldn’t hear what they were saying. I took the tissues away from my nose and checked them. The bleeding felt like it was slowing down.

I tossed the bloody tissues into the basket next to my school bag. As I grabbed more tissues from the box, I noticed blood from my nose had splattered all over my T-shirt.

Great.

“That’s a brave girl,” Miss Johnette was saying to Abigail. What was Abigail being brave about? I tilted forward again, keeping the fresh tissues on stand-by.

“Okay, which arm are you in the mood for today?” Miss Johnette asked.

“The left,” Abigail said.

I heard a rustling sound, a ‘Go Hornets!’, a giggle, and a plasticky click. What were they doing? And ‘Go Hornets’? Hornet was the name of our school mascot and our basketball team.

“There you go,” said Miss Johnette. “Right. Just sit there for a minute and let me check on my other patient.”

I quickly shut my eyes and made my face blank, trying to look like I hadn’t been listening.

“Hey, Tanner,” she said. “Let’s take a peek.”

I opened my eyes as she snapped on a new pair of gloves. She held my face in her hands and tipped my head back.

I think she was looking up my nose. Being a nurse must be weird sometimes.

“You are almost ready to go.” Miss Johnette swabbed at my face with a damp paper towel, and I caught the scent of rubbing alcohol. She stepped back, looked me over, and then smiled. “I think you’ll survive. Feel okay?”

“Yeah, just...” I looked down at my shirt.

“That’s not a great look. Do you have another shirt?”

I thought.

“My basketball jersey’s in my locker,” I told her. “I can put it over my T-shirt to hide the blood.”

“Smart thinking. Go Hornets!” Miss Johnette said, with

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a grin. “Okay, let me write notes for you and Abigail, and you can both head back to class.”

I followed her over to her desk, where Abigail was waiting. She looked at my shirt. “Did you knock out a tooth?” she asked.

“Nosebleed,” I said.

“Oh,” she said, looking disappointed.

“Abigail, this is Tanner,” Miss Johnette said, as she scribbled on two slips of paper. Abigail gave a little wave, and I waved back. Miss Johnette handed us each our slips. “Okey-doke. Back to class, both of you.”



Chapter 9

“I like Miss Johnette, don’t you?” said Abigail as we walked together down the hallway. “She’s much nicer than the nurse I had at my elementary school. She always acted like giving me my shots was such a big deal. Like ... “Ugh, Abigail, why are you here?” I don’t think she liked kids at all, but if you don’t like kids why work in a school? Miss Johnette definitely likes kids. Don’t you think?”

Abigail was talking really fast and swinging her plastic bag back and forth. She had brown hair and it was up in pigtail buns.

“Yeah, she’s really nice,” I said. “And yeah, she seems to like kids.”

Giving her shots? What shots? I knew better than to ask. Didn’t want to make her feel awkward.

“Do you get a lot of nosebleeds? I used to get nosebleeds when I was little but I don’t get them anymore,” she said.

“Um, sort of...” I said, vaguely.

“Are you afraid of blood? I’m not.” She glanced at me.

“I have to stick my finger with a tiny needle a couple of times every day and test my blood. I can’t be afraid of blood. Some-girls act like blood is so spooky but I’m not scared of anything.”

I grinned, more surprised than anything. I didn’t know many girls that talked about blood so much. That talked so much period!

Abigail lifted her chin, like maybe she thought I was smiling because I didn’t believe her.

“If you got another nosebleed right now, I wouldn’t be freaked out at all,” she said confidently.

The way she looked at me, straight in the eye, I did believe her. And I told her so.

But, what about this finger-sticking thing?

It seemed like something to keep private. Like something I’d want to keep private, that is. So I hesitated.

“What?” she said, when I looked at her.

Then again, she was the one who’d brought it up.

“Why ...? Do you mind if I ask ...?” I said.

“What? Spit it out.” She grinned and swung her plastic bag.

“Why do you have to test your blood?” I asked.

“I have diabetes,” she said, with a shrug. “Heard of it?”

I shook my head.

“It’s this thing I was born with. A dis-ease.” She drew out the word, looking at me, expectantly. When I didn’t react, she added, leaning in, “But don’t worry. It’s not contagious.”

And I fell for it. “I’m not worried,” I blurted out quickly. “Really, I ...” and stopped when she grinned a “gotcha” grin.



I laughed. Okay, one-nothing for her.

“So,” Abigail continued, “my body doesn’t make this stuff called insulin, which helps you like...eat sugar, but in your blood.”

She waved her hand. “I could explain it more scientifically, but you might think it’s boring. But anyway, basically, it means I need injections of insulin a few times a day because I don’t actually...have any of my own insulin. I bring some insulin pens to school just in case I need a little extra while I’m here.”

“That’s what’s in your bag?” I asked.

“Correct-a-mundo!” She grinned and lifted her bag. “Yup. It has a cartridge of insulin and a dial so we can choose what dose. There’s a needle at the tip. It’s all-in-one. Miss Johnette does it for me if I need some at school.”

Suddenly, I got it.

“Oh! ‘Go Hornets,’” I said.

She stared at me.

And, ding! I figured it out.

“You said, ‘Go Hornets’ when Miss Johnette injected you with the needle, cuz the needle is like a hornet stinger,” I said.

“Correct-a-mundo again,” she said, grinning. “And also cuz I’m a basketball fan, and our school team is the Hornets,” she added. “I say ‘Go Hornets,’ when I inject myself at home too.”

“Wait, what? You inject yourself?” I said. I stopped in surprise. “Really?”

“Yup,” she said proudly. “Every day.” She looked at me, trying to gauge my reaction. “I’m not scared of needles at all.”

“I believe you. I’m not either,” I told her, quickly, and started walking again. “I have to inject myself with medicine too. But not every day like you. Every other day.”

I hadn’t even thought about telling her. But now I had. Her eyes lit up. “Really? Do you have diabetes too?”

I shook my head. “No, I have a bleeding disorder. It sounds a little bit the same. I have a part of my blood that’s missing, it doesn’t clot. So I get nosebleeds and...other kinds of bleeds and things like that. But I’m not afraid of needles either because I’ve been getting poked since I was a baby.”

Abigail nodded, then she made big eyes at me. “But your bleeding disorder is probably con-tagious. And makes you different in some totally weird way, right?”

I laughed.

“Tanner, it’s cool there’s two of us in this school!” she said. “We’re probably the only kids here who don’t care when the doctor gives them a shot because we’re all, ‘oh big deal I do this every day.’”

She grinned, and I grinned back.

“Hey, this is my class, Tanner.” she said, pointing at room 105. “See ya later.”

“Yeah, see you, Abigail.” I said.

“Call me, Abby, okay?” she said, waving. I headed to my locker to throw on my basketball jersey and cover up my blood-stained T-shirt before catching the last ten minutes of English class.



Chapter 10

After school ended for the day, I threw my English book and notebook in my locker. Reaching in to retrieve my gym bag, I asked Jax casually, “Hey, do you know this girl Abigail? I think she’s in our grade.”

“Nope,” said Jax. He looked at me, curious.

“Okay,” I said, quickly. “Cool. So, see you in the gym in a bit?”

“Yeah, I better go change,” he said. “Hey, Tanner. Good luck, buddy. Hope you win. You’ve worked so hard. You deserve it.”

I blushed and luckily, before I could respond, he had hurried off to the music room, band uniform in hand.

Our marching band doesn’t have the fancy uniforms like the high school band has, with hats and stuff like that. Instead they wear yellow and black striped t-shirts. Our basketball uniform is also yellow and black. My dad teases me that we all look more like bumblebees than hornets, but I like the uniforms. Victoria does too, but she also loves bumblebees.

I hurried down the hallway toward the gym doors. My ankle ached.

Coach Velasco was there, standing by the door with a clipboard. As he looked up at me, I made sure not to limp, even a little.

“Seven!” he said, happily.

“Coach.” I responded.

Should I do it? Speak to him now?

Then behind me came Jason’s voice. “Coach, you ready?” His voice broke between “you” and “ready.” Jason was the tallest on our team, the skinniest, and his voice had been changing forever.

“You know it, forty-four.” replied Coach Velasco.

Jason put his arm around my shoulders and together we walked into the gym. Thirty or so students were already in the bleachers, some from our school wearing yellow and black, and others wearing gold and blue, the Cougar colors, I guess. Some parents were there too, but not mine yet.

We went directly into the locker room, which was just inside the gym.

Most of our team was already there, fist-bumping and high-fiving, chatting as they got changed. Luis, Dom, Charles

...

Omar and Marcus already suited up and were looking at Omar’s phone. I peeked. In a video, a kid was jumping off the roof of his house and backflipping into a pool.

“Yes!” shouted Omar. “Dude!”

They saw me, smiled, and made room on the bench. I set my bag down and automatically changed out of my jeans, took off my jersey and my blood splattered T-shirt, then put

the jersey back on.

The room was buzzing with energy and hope. My mind was racing. Play or not play? Try or give up? Neither option was a good one.

A few more team members came in, hurrying, and then Coach Velasco.

“All present and accounted for,” he said. Then, he went on, loudly, “Now, who are we?”

“The Hornets!” we cried.

“Who?” he yelled even louder.

“The Hornets!” we yelled back.

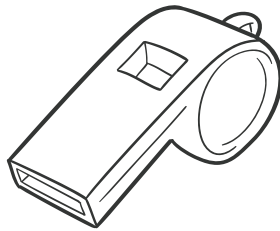
“What do we do?” Coach Velasco bellowed.

“We sting!” we roared back to him.

“All right, Hornets, you know our goal. You know our plan. You’re ready to win this,” Coach said. “Have fun. Play safe. And go win this thing!”

Everyone jumped up, hooting, and filed out of the locker room doors.

Everyone but me.



Chapter 11

“Seven. What’s up?” Coach asked.

My teammates didn’t know about my bleeding disorder but Coach did of course. How could I explain how my ankle felt but still convince him it was okay for me to play? I knew I should talk to him. I knew it. But what if he said no. That I had to sit it out?

“Seven?” Coach asked, frowning.

I thought about Abigail saying, “Go, Hornets.” About the hours and hours I’d been practicing for this opportunity.

“Everything okay?” Coach asked.

“Yup,” I said. “Sorry, Coach. Spaced out for a minute there.”

He gave a quick nod, still frowning, looking like he might say something more. So I hurried out of the room.

Four kids in yellow and black striped t-shirts with snare drums slung around their necks stood along the sideline. They were rattling out a rapid staccato beat.

I joined my team. We got on the court, and we began

warming up.

Our opponents were getting changed in the girl's locker room. A moment later, the Cougars came jogging through the gym doors. They began warming up on the other side of the gym.

More band members joined the drummers and began playing. I saw Jax, his eyes bright, cheeks puffed out, blowing into his trumpet with everything he had.

We locked eyes and he stopped playing for a second to give me a thumbs-up.

I was trying to take it easy on my ankle. Trying to ignore that it was still sore.

The stands were filling. We'd never had so many people come to watch any of our games before.

Quickly, I scanned the crowd again, Mom and Dad still weren't here. Phew. What would they think if they saw me on the court?

Then I instantly felt bad. What did it matter if they weren't here yet? They'd be here soon, because they'd promised to come and I knew I could count on them. And they thought they could count on me. To be responsible. To do what was right for my health. And here I was, thinking of doing something stupid. Desperately wishing I could play.

"Tanner! Go Hornets, T!" It was Victoria.

My anger at my sister came flooding out, and I threw the ball hard at Jason. He barely caught it, looking at me in surprise.

Immediately I regretted it. I put up a hand, waved a sorry.

And suddenly, all my anger vanished. I could apologize



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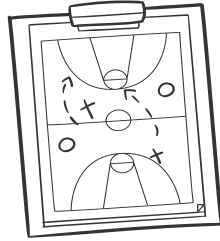
to Jason so easily. Why couldn't I be nicer to my own sister? It wasn't her fault I had this bleeding disorder. It wasn't even her fault I hurt my ankle. It was an accident.

I'd been complaining about life being unfair to me. But I was the one being unfair.

I turned to Victoria and smiled. Waved. Gave her a thumbs-up.

And she beamed back at me. My little sister.

And standing there, I finally accepted it. I couldn't play in the game today.



Chapter 12

I stepped off the floor and headed for Coach. Put my hand on his arm.

We moved into the doorway where it was a little quieter.

“I had a bleed four days ago, Coach, after our last game. We didn’t have a practice this week and I thought the days off would take care of it. My ankle. But it hasn’t. It’s still sore,” I said. “I’m sorry for not telling you sooner.”

It came out all in a rush.

I waited for him to get angry. To tell me I couldn’t play. That I was benched.

But he only frowned for a moment, and then his face cleared. “Okay. I accept your apology, seven.” Coach said. “Now, what do you want to do? You tell me.”

I blinked.

“Coach ...”

He waited, waited for me tell him what was best.

It was hard for me to say. “I don’t think I should play.”

Coach nodded. “Okay, then.” He nodded again. “Tanner

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I know it's hard to sit out a game like this, and I wish you'd told me sooner."

I bowed my head. "Sorry. You're right. I should have."

He went on, "But you can still help our team. You can cheer them on, be with your teammates. They're counting on you to be here. You're our super seven."

"I will." I said. "Of course, I will." But deep down, I knew they probably wouldn't care much. They had enough power without me. They wouldn't notice I was on the bench. I was the one who was missing out.



Yes, I watched the game. Yes, I paid attention.

The whistle blew. The referee threw the ball high. The Cougars' center was even taller than Jason, but Jason won the jump ball and tipped it to Omar. And we were off. At least, the players on my team were. Me, I was a bench-warmer, permanently.

My parents had come in right after I saw Victoria. Mom had blown me a kiss. The three of them were sitting in the middle of the stands, watching the action closely. Watching me do nothing.

Yes, I watched the game. I wanted my team to win. Of course.

I admit. I didn't feel angry anymore. But I didn't feel excited or happy. I felt ... sort of empty, I guess.

The first quarter went okay. But we couldn't get ahead.

And at half-time, we still were behind. It was close, but the Cougars didn't seem to make any mistakes. They were fast.



They could dribble and pass. They were really good.

I sat on the bench and tried not to feel left out while Coach strategized with my teammates and tried to keep their spirits up. I watched the band come onto the court and play. They got everyone in the stands cheering. Even Jax was participating more than me.

After the third quarter, they were ahead even more.

Coach Velasco drew me into the team huddle, talking tactics and strategy. But I wasn't really listening. I tried my weight on my left ankle. It ached.

The band played some really rousing music from the bleachers. Jax played a solo.

All the spectators were standing and cheering. Victoria waved to me and I waved back. But this time, I couldn't manage a smile.

Kid with rare bleeding disorder over here. That's me. Side-lined. What if my whole life was like this?



Chapter 13

“You’re a Hornet?”

“Huh?” I turned. It was hard to hear with the crowd and the band.

“You’re a Hornet! You didn’t tell me,” said Abigail.

“Abigail! What are you doing here?” I asked.

“Hey, call me Abby, remember?” She grinned. “My brother’s on the team,” she said. She pointed at Charles. “And I’m a fan. I told you. I love basketball. You’re on the team! Why didn’t you tell me earlier?”

“Yeah, well. I’m on the team sort of,” I said, with a shrug.

“What do you mean ‘sort of’?” she said. “You’re wearing a jersey. You’re number seven. You seem to like keeping secrets.”

I smiled a bit. “Yeah, I guess. But I wasn’t sure I’d be playing tonight. I had a bleed in my ankle on Monday. It still isn’t better.” I pointed to the bench. “So that’s my position for this game.”

She frowned. “You’re sounding a bit sorry for yourself.

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Like, because of your disease.” She poked me gently, making me grin.

I nodded. “Yeah, true. I am actually feeling sorry for myself right now.”

But not as sorry for myself as I’d been feeling a few minutes ago. It felt kind of good to explain to someone why I wasn’t playing.

I bet your team isn’t happy about it either,” she said. “Do they know what’s up with you?”

“No,” I said. It struck me that I hadn’t really explained. I was sitting out, but they didn’t really know why. They didn’t know how much I wanted to play. How some normal dumb injury was keeping me from pulling my own weight, from playing in our final championship game.

The whistle blew. The final quarter was beginning.

Abigail nodded. “Go, Hornets.” she said to me, with a smile.

“Go Hornets.” I replied. And then I repeated it with feeling. “Go Hornets!”

As my team got up to take the court, I hurried over to Coach Velasco.

“What can I do, Coach?” I asked, urgently. “I want to help us win! How can I help?”

He smiled a big smile. “Cheer ‘em on, seven. They need your support. They’re feeling frustrated and down. They need you to tell them they can win.”

So I did. I stopped moping and I cheered and cheered.

“Get ‘em, Omar, Marco!” I cried.

I yelled encouragement as our players came off and went on.

“You got this, Jason!” and “You’re working hard, fourteen!”

I stayed positive. I watched Coach and tried to support what he did and said.

The guys gave me some hand-slaps when they came off. I buzzed to them like a hornet and handed them water bottles as they sat down.

“Nice shot, thirty-three!” and “Good job running the break, Luis!”

Our score began to inch up.

When players were on the bench, they began to nod and stamp their feet enthusiastically. The ones on the floor seemed more confident. They tried some more difficult plays and were successful more times than they weren’t.

“Go Hornets!” the crowd yelled.

The gap closed.

And finally, we were in the final twenty seconds of the game. The Cougars were ahead but only by one point. If we got a basket, we’d win.

I was on my feet, along with everyone in the crowd, the band, all our players. I could hardly breathe.

“Ten seconds!” Coach shouted. “Nine, eight ...!”

“Go Hornets!” I yelled, when Luis got the ball. He dribbled down the court and stopped. Jason was in the clear, left arm waving. “I’m open! I’m open!”

Marco was in the clear. “Me, Luis! Me!”

Luis looked at Jason. He looked at Marco, who was in the clear, and he actually turned and looked at me, on the bench. He gave a nod.

And sure, enough. I knew his play and so did Luis and

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so did Marco, but the Cougars? No way.

So when he drilled the ball at Marco, they were totally surprised.

Six seconds until the buzzer, six ...

Marco caught it, spun on a dime.

“Three, two ...”

Lifted off, and ...

“One.”

... shot the ball!

The basketball arced through the air as the buzzer sounded.

The crowd yelled. I held my breath.

The ball went through the hoop, swish!

We all started cheering and rushed the court, our fans in the crowd too. We did it. Won the game. Won the championship. My team and I had won.





Chapter 14

Mom, Dad, and Victoria let me talk about basketball and the game all during dinner. They all said they were really proud of me and I felt proud of myself too.

But I was pretty tired and my ankle was achy. I must have jumped up and down on the sidelines too much in that final quarter. If I actually played, I'd probably be in lots of pain right now.

I grabbed an ice pack from the freezer and headed to my room to watch a movie on my laptop. I settled into my bed, my foot up on a pillow, the ice pack on top of it.

Before the movie started, Mom came in.

She ruffled my hair and sat down on my bed.

"I almost tried to play in the game, Mom," I found myself saying. "But then I decided not to."

I wasn't sure why I'd told her. I thought maybe she'd be mad. But it felt good to talk about it. No more secrets.

Mom didn't look mad. She put her hand on mine.

"Also, next year, when basketball starts up again, when I make

it onto the team again,” I said, confidently, “I’m going to tell my teammates. Tell them about my bleeding disorder. I think I need to. Then, if I need to sit out again, they’ll understand why. It will still feel bad, but at least they’ll know I’m not letting them down on purpose.”

“Sounds like a good idea.” Mom squeezed my hand and nodded.

“Tanner,” Mom said, “I wish you knew someone who could understand what you’re going through. I try my best. But I know it’s not quite the same.”

I told Mom about Abigail. Abby. I explained that I’d told her today about my bleeding disorder after she told me she had diabetes. I didn’t tell her that I also just think Abby is ...well, cool.

“It felt good. Abby seemed to really get it. But it’s not quite the same, Mom. I wish I knew someone with a bleeding disorder.” I laughed. “Maybe I wish these disorders weren’t quite so rare!”

Mom grinned. “Well, honey,” she said, “I happen to have a surprise.”

She pulled out a pamphlet and handed it to me.

“I’ve applied for you to go to a summer camp for kids with bleeding disorders this summer. It’s put on by a chapter that’s affiliated with the National Hemophilia Foundation. You know about the foundation, right?”

I nodded.

“The camp has all kinds of activities—rope courses, archery, swimming, and, yes, basketball. It’s for kids with bleeding disorders and siblings can go too, even if they don’t have a bleeding disorder themselves.”



“Seriously? A camp with other kids like me?” I said.

“Yeah, but you can think about it. I applied, but you don’t have to go, Tanner,” Mom said. “There’s lots of time to decide.”

“Wow, Mom. I don’t need to think about it. I’m in!” I said, reaching over and hugging her. “Thanks so much.”

She laughed. “Okay, honey. We’ll talk about it some more.”

“Tomorrow?” I asked.

“Sure. Tomorrow.” she said, grinning. She got up. “Are you okay? Want another ice pack?”

“No, I’m good,” I said.

“Okay. Don’t stay up too late, Tanner. Love you,” Mom said.

A moment later, I was on my feet, tapping lightly on Victoria’s door. My sister was already in bed with her light out, but she said, sleepily, “Yeah? Tanner?”

“Hey, Vic,” I said, plopping down on her bed beside her. “Want to go to camp in the summer with your favorite brother in the whole world?”

Victoria smiled. “Okay,” she said, and she added in a serious voice, “You know, you are my favorite brother in the whole world.”

I squeezed her toes as I said good night and headed back to my own room. Foot on pillow, ice pack in place, I thought about the camp, the game, the day, Abby, Jax, my family, and my life.

Super Seven for sure. One of a kind, but a very lucky guy.

THE END

Tanner is 12 years old, crazy about basketball, and has a rare bleeding disorder.

His team is playing in the championship finals, but an unexpected bleed means Tanner has some tough decisions to make. With the help of a new friend, Tanner figures out a way to help his team on the court – and learns there's more than one way to be a champion.

Do you have questions about living with a rare bleeding disorder?
Please contact HANDI, NHF's information resource center:

- Call 1-800-42-HANDI
- Email handi@hemophilia.org
- Submit a request for information form via the "Contact Us" section of the NHF website



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