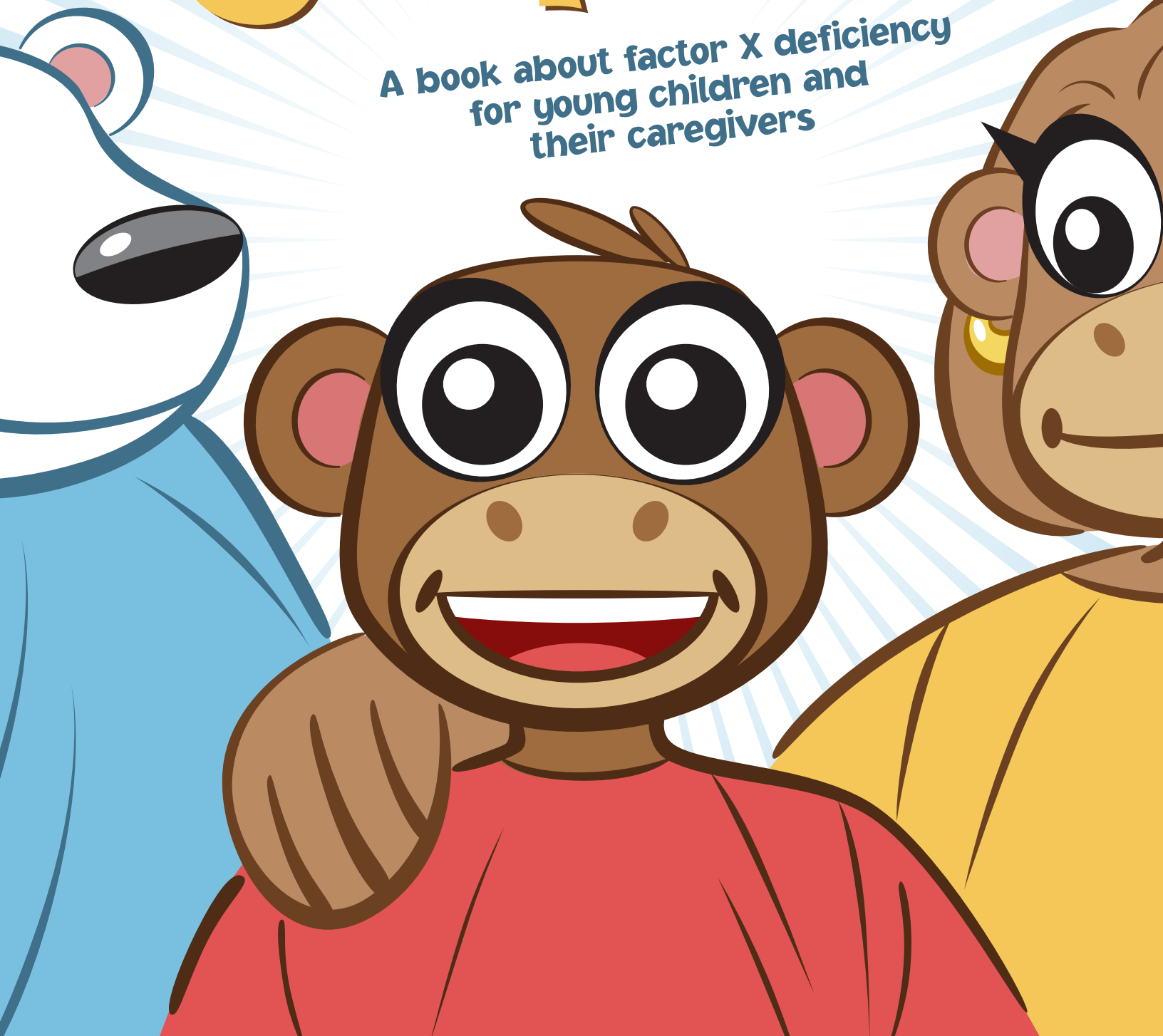


Alex's Surprise

A book about factor X deficiency
for young children and
their caregivers



One sunny morning, Alex is eating breakfast.

Alex's mom comes into the kitchen and says, "Good morning, Alex. You know Riley from school, right? And this is Riley's mom."

"Hi," says Alex with a wave.



Alex's mom continues, "Riley's mom and I need to work on a project today. Riley is going to run some errands for us. Why don't you go, too?"

"Sure," says Alex, putting his bowl and spoon in the sink. "Just let me get my stuff."

“Hey Alex,” calls Riley. “What’s with the elbow and knee pads? Are you afraid of crashing?”

“Yeah, actually. A little,” Alex sighs. “It’s a big deal if I get hurt. I have something called factor X deficiency.”



“Factor X deficiency? What’s that?” asks Riley.

“Factor X helps you stop bleeding. My body doesn’t make enough factor X. So it’s hard for me to stop bleeding if I get hurt.”



“You’re the first person I ever met with factor X deficiency,” Riley says. “Do a lot of people have it?”

Grinning, Alex replies, “I’m one in a million...really! Factor X deficiency is rare. Only about 1 person in every million people have it.”

“Wow, that’s cool!” says Riley, impressed.

“It’s just part of who I am. Like some kids wear glasses, or my cousin has asthma. Everybody’s different.”

Arriving at the toy store, Riley stops. “My mom asked me to pick up a package. Would you mind waiting here with the bikes?”



After a few minutes, Riley comes out with a box. Alex wonders what's in it but is too polite to ask.

Putting the box in the bike trailer, Riley says, “Let's go!”

Riding down Main Street, Riley turns to Alex. “Is there a way for you to get better?”

“Well,” Alex explains, “Right now, there is no way to fix my body so it makes factor X. But there is a special medicine. It gives me factor X, so I stop bleeding.”



“Do you have to swallow pills? I’m not good at that.”

“Nope. I get the medicine through a needle in my arm.”

“Yikes!” yells Riley. “A needle? That’s worse than pills!”

“Not really. My mom is good at it, so it only hurts a little. And, when I’m older, I’ll be able to do it myself.”

Riley looks at Alex with awe. “Wow, I can’t imagine sticking myself with a needle.”

“You get used to it,” Alex replies. “Where are we going now?”



“We’re here,” says Riley, heading for the store. “My mom called ahead so I need to pick up what she ordered.”



When Riley returns with a shopping bag, Alex really wants to ask what’s going on. But Riley has another question.

“How do you know when you need your special medicine?”

“It’s when I have a bleed,” says Alex, getting back on the bike. “Like a cut or a scraped knee. Those are the easy ones...when I can see that I’m bleeding. It’s harder when I fall or bump into something, because I might not see any blood. My mom says that I can still be bleeding inside.”

“Huh? Bleeding inside?”

Riley looks confused.

“How would you know?”



Alex stops pedaling and explains. “When I’m bleeding inside I might notice it in my joints, like my knee, elbow, or ankle. My joint might get big or puffy. And it might feel warm or be harder to move.”

“My parents say it’s really important to tell them if I hit my head. There’s always a chance of bleeding in my brain. So, it’s important for me to have my special medicine right away.”



Riley says, “Gee, it sounds like you have a lot to worry about.”

“Not really. I just need to pay attention and tell my parents or another adult when I fall or get hurt. Hey...there’s a playground over there. Do we have time to stop for a few minutes?”

“Yes,” says Riley with a smile. “Race you to the swings!”

On the swings, Riley wonders aloud about what Alex can do. “So, can you play board games?”



Alex replies, “Of course, silly. People don’t get hurt playing board games.”

“What about soccer?”

“Sure, but I have to be careful.”



“What about baseball?”

“Same.”

“What about skydiving?”

Alex laughs. “Doesn’t matter. There is no way that I’m jumping out of an airplane!”

“Me, either!”
says Riley, laughing
along. “We probably
better get back to
our errands.”





Back on the bikes, Alex says, “Tomorrow I have to go to the doctor.”

“What kind of doctor?” asks Riley. “Is it the dentist? I don’t like the dentist.”

“Nope, it’s my hematologist. That’s the doctor I see for my factor X deficiency. Hematologists know about blood.”

“The doctor checks me over and asks how I feel. We talk about any bleeds that I’ve had. My mom brings along a list that we keep of how many bleeds I’ve had and how bad they were.



And the nurse usually takes a sample of my blood. It only hurts for a second.”

Alex finishes, “Sometimes I have to go for other tests to see my insides.”

“Your insides?” Riley blurts out, a little scared.

“How do they do THAT?”

“Don’t worry,” says Alex. “It’s only a picture. It doesn’t hurt at all. Sometimes I have X-rays, which are fast. Other times I have an MRI. Then I have to lie very still in a big, noisy tube. One time I even got to look at the pictures!”





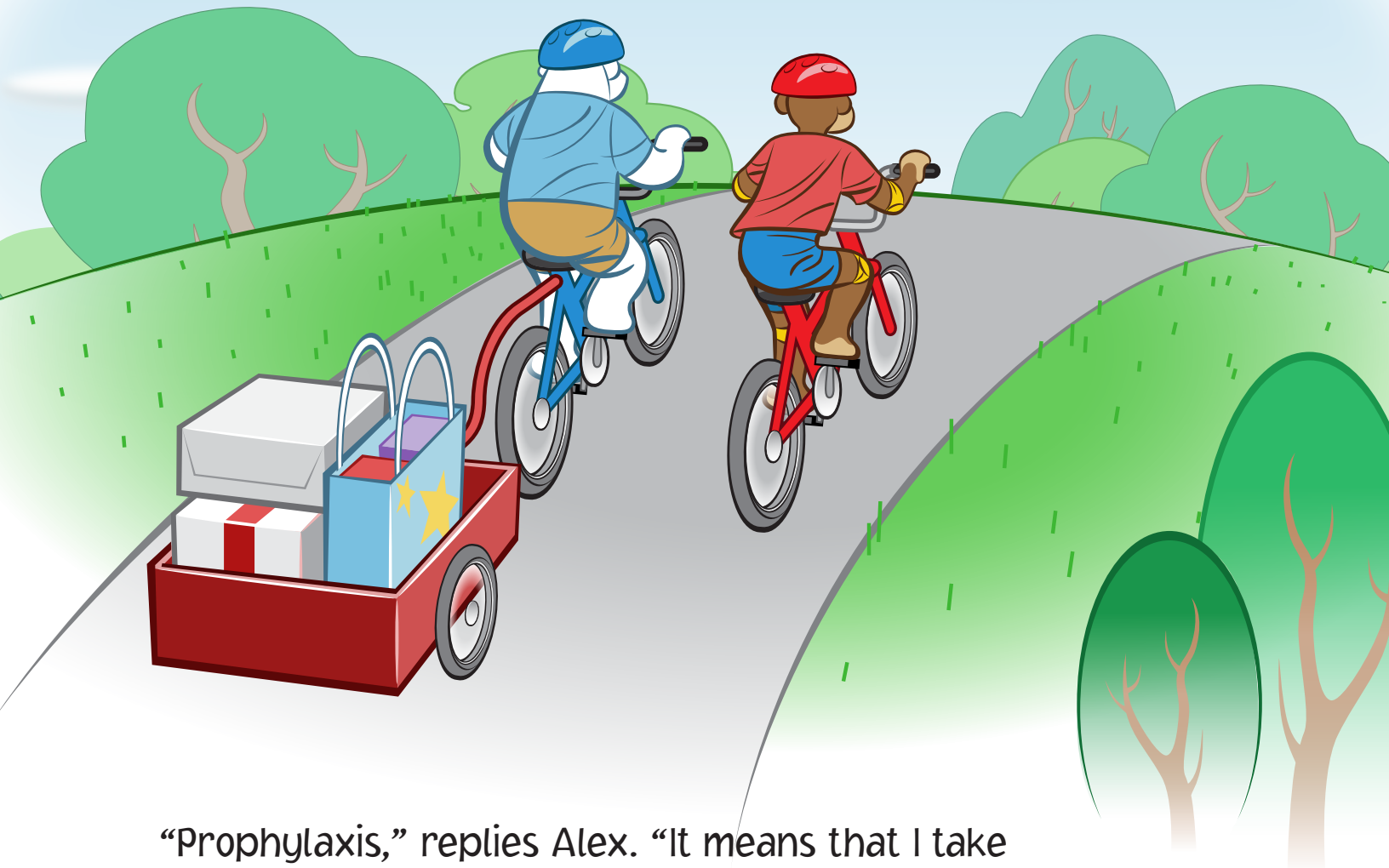
“That’s something,” says Riley. “Look, here’s our next stop. I’ll only be a minute.”

When Riley comes back with a big bakery box, Alex can’t contain himself any longer. “What’s going on? Is there a party?”

“Yep,” replies Riley. “For somebody my mom knows. Just one more stop. Let’s go.”

Pedaling hard up a hill, Alex says, “At my last visit, the hematologist told us about something new. It’s called prophylaxis.”

“Pro-fi-what?” asks Riley, a bit out of breath.



“Prophylaxis,” replies Alex. “It means that I take my medicine a few times a week whether I have a bleed or not. That way my body can stop a bleed as soon as it starts or prevent it all together.”

“Is that a good thing? Sounds to me like a lot more needles,” says Riley.

“It is a good thing. Think of it like the seatbelt in a car.” Alex pauses and takes a deep breath. “It’s always better to stay safe, just in case. Because forgetting, just once, could be a problem if an accident happens.”

“Well, when you put it that way,” says Riley, making it to the top of the hill. “It makes a LOT of sense.”



“Yep, I think prophylaxis is a really good idea. My parents and I have talked about it, and I’m going to tell the doctor tomorrow.”

Riding into the park, Riley says, “We’re here!” “Thanks for telling me about your factor X deficiency. I hope your visit to the doctor goes well tomorrow.”

“Thanks,” replies Alex with a smile. Looking toward the picnic shelter, Alex adds, “Hey, is that party today?”

“Yep,” says Riley, steering toward the party. “Let’s go over and drop off the stuff.”





As they ride closer, Alex begins to see familiar faces. “Hey—there are some kids from my class here. I also see the family from down the street. And there’s your mom...and my mom and dad!”

SURPRISE!

HAPPY BIRTHDAY ALEX



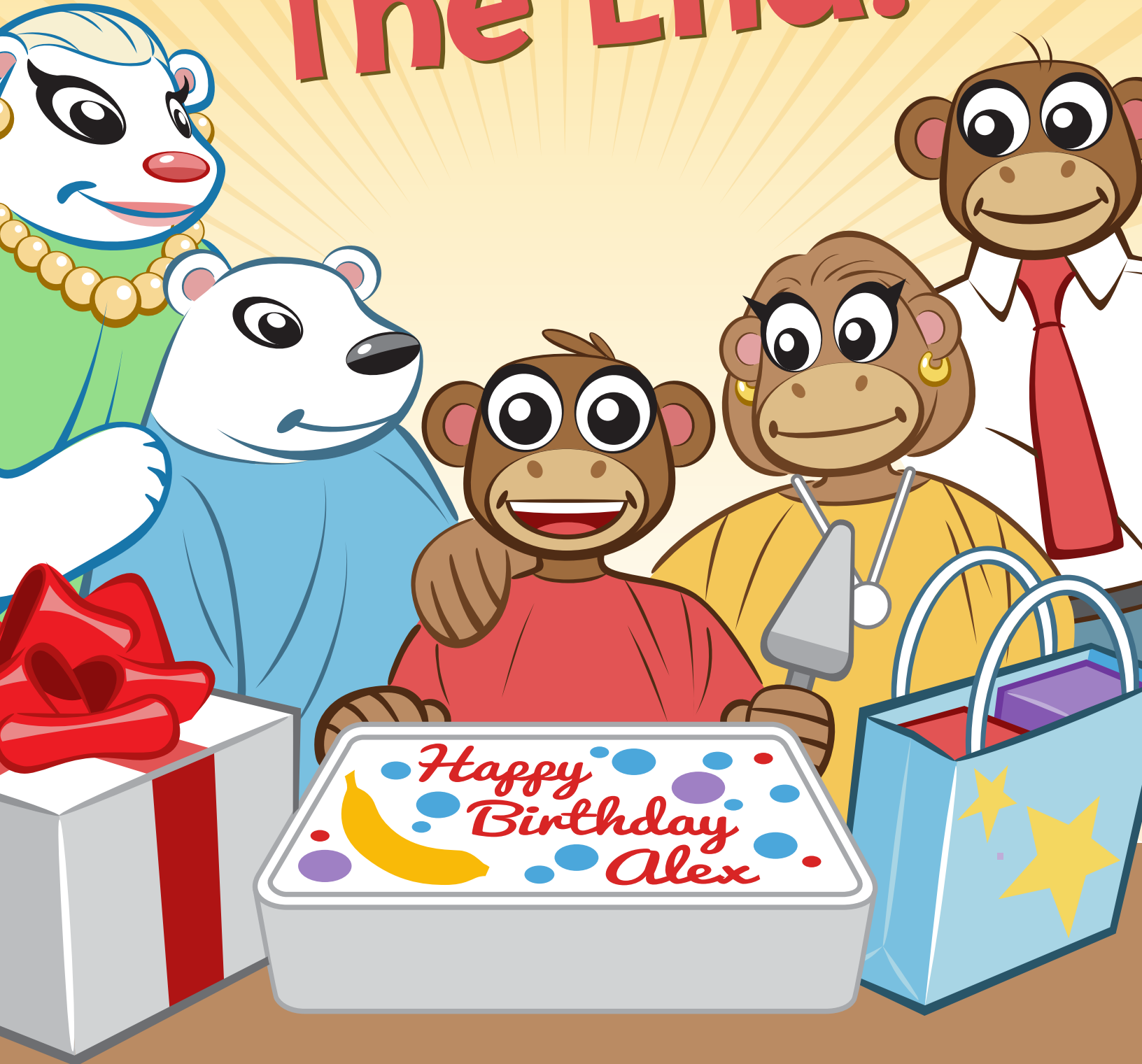
“But..., but...” Alex sputters. “But my birthday isn’t for 2 weeks yet!”

“That’s right,” says Alex’s mom. “But if we waited until your birthday, it wouldn’t have been a surprise!”

Grinning, Alex replies, “You’re right. This is going to be the best birthday ever!”



The End!



Factor X Deficiency: Q & A for Parents and Children

1. Why do I bleed a lot?

You bleed a lot because your body doesn't make enough of a special protein called factor X.

2. What is so special about factor X?

Factor X helps you stop bleeding when you get hurt.

You have something called factor X deficiency. That means that your body doesn't make enough factor X. So, it's hard for you to stop bleeding if you get hurt.

3. Why do I have to be more careful than other kids when I play?

You have to be more careful because it will be harder for you to stop bleeding if you get hurt. You also need to avoid doing things that are very likely to lead to injury, like wrestling or tackle football.

4. Are there other people like me?

You're one in a million...really! Only about 1 person in a million does not have enough factor X. It's just part of who you are. Like some kids wear glasses, or have asthma, or use a wheelchair.

5. Will I see a special doctor?

Yes. You will see a hematologist. That's a type of doctor who knows about blood.

6. What will happen when I see the hematologist?

The doctor will check you over and ask how you feel. You'll talk about any bleeds that you've had. We'll bring along the list of how many bleeds you've had and how bad they were.

7. What other tests will I have?

That depends on what the doctor thinks you need. You might have an X-ray to take a quick picture of your insides. Or you might have more detailed pictures taken using an MRI machine. Then you'll have to lie very still in a big, noisy tube for several minutes.

8. How will I know if I'm bleeding inside?

When you're bleeding inside you might notice it in your joints, like a knee, elbow, or ankle. The joint might get big or puffy. And it might feel warm or be harder to move.

It's really important to tell a parent or another adult if you hit your head, even if you feel okay and don't see any blood. That's because there's a chance you could be bleeding in your brain.

9. Is there a way for me to get better?

Right now, there is no way to fix your body to make enough factor X. But there is a medicine that gives you extra factor X when you need it.

10. How do I take the medicine?

You will get the medicine through a needle in your arm. I or another adult will give it to you. When you're older, you'll be able to do it yourself.

11. Does it hurt to get the medicine?

Sometimes, especially when the person giving the medicine is still learning. But it's important to be brave, because the medicine will help you stop bleeding.

12. What happens if I don't take my medicine?

Taking the medicine is the only way for you to stop bleeding. If you don't take it, you might not be able to do things like run and play with your friends.

13. How often will I take my medicine?

Some people take the medicine only if they know they have a bleed. But other people take it a few times a week no matter what. That means more medicine and more needles, but then your body is ready to stop any bleeding as soon as it starts.

“Alex’s Surprise” is a book for preschool and elementary school children to read with their parents or caregivers.

With a fun and engaging story, “Alex’s Surprise” explains factor X deficiency in simple, clear language appropriate for people of all ages.



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