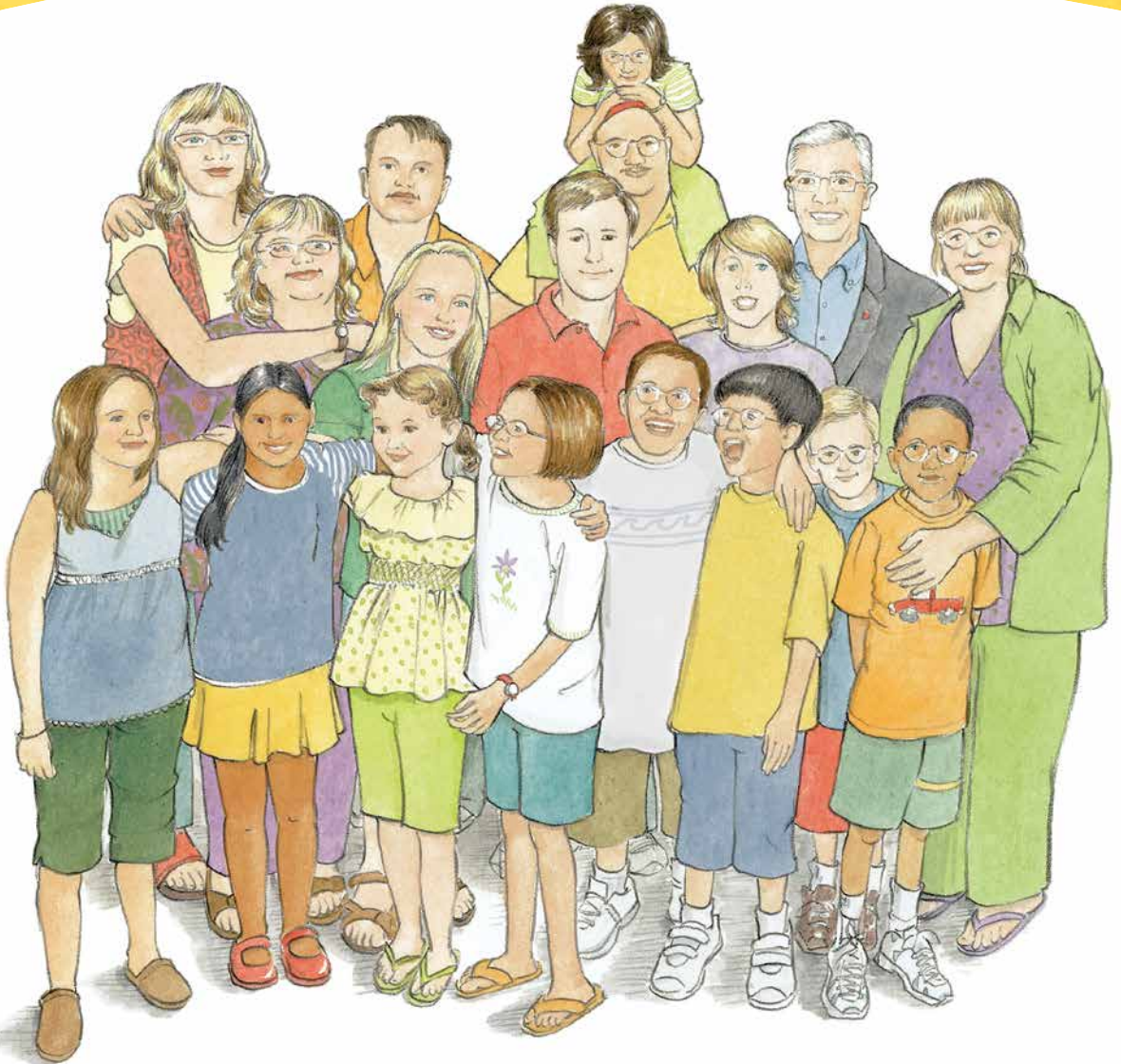


# Marfan Syndrome A-Z



Created by The Marfan Foundation

Illustrations by Lori Mitchell

# Marfan Syndrome A-Z

## The Marfan Foundation

Illustrations by Lori Mitchell

Design by Lonn Lorenz

### Dedication:

This book is dedicated to the children of our Marfan family across the nation, who are all connected by a special gene.

May it help you realize who you are, why you are special, and that you have many friends who are just like you, with names from A to Z.

There is magic in knowing that you are not alone. Together, with your friends, family, doctors and the help of The Marfan Foundation, you will find out how to live well, love always, and laugh a lot through your life's journey with Marfan syndrome.

We are grateful to the caring doctors, families, and especially the children at The Marfan Foundation Conference at Stanford University, who allowed us to use their images to illustrate this book.




THE **MARFAN**  
FOUNDATION

Know the signs. Fight for victory.

# More than meets the eye!

As you are reading, see how many items starting with each letter you can find on that page. For example:

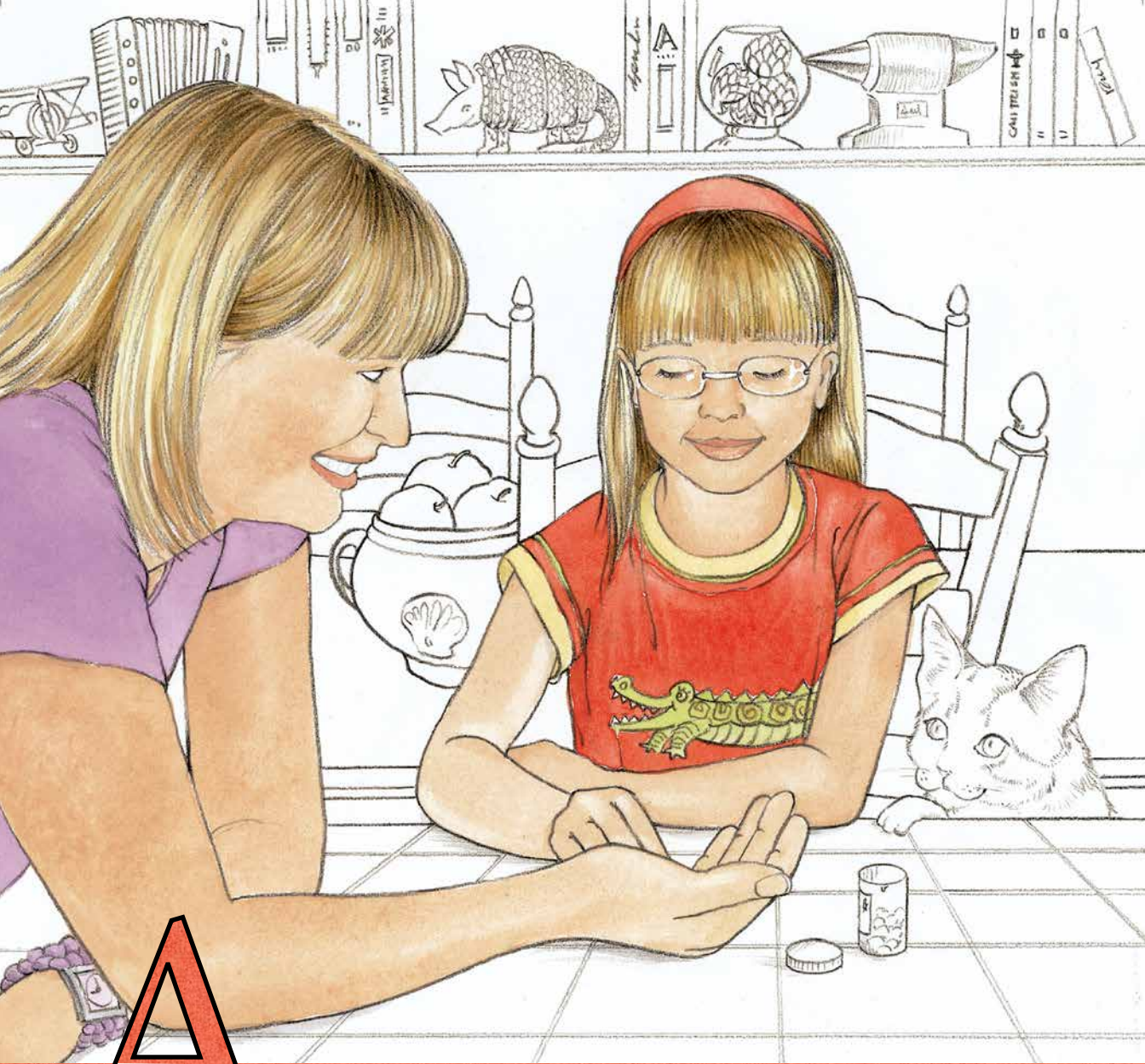
Do you see the armadillo  on the “A” page?

What about the daisy  on the “D” page? Find it and other items that start with D on that page!

Explore each page and find items starting with the letter of that page. Check the list in the back of the book if you need a hint.

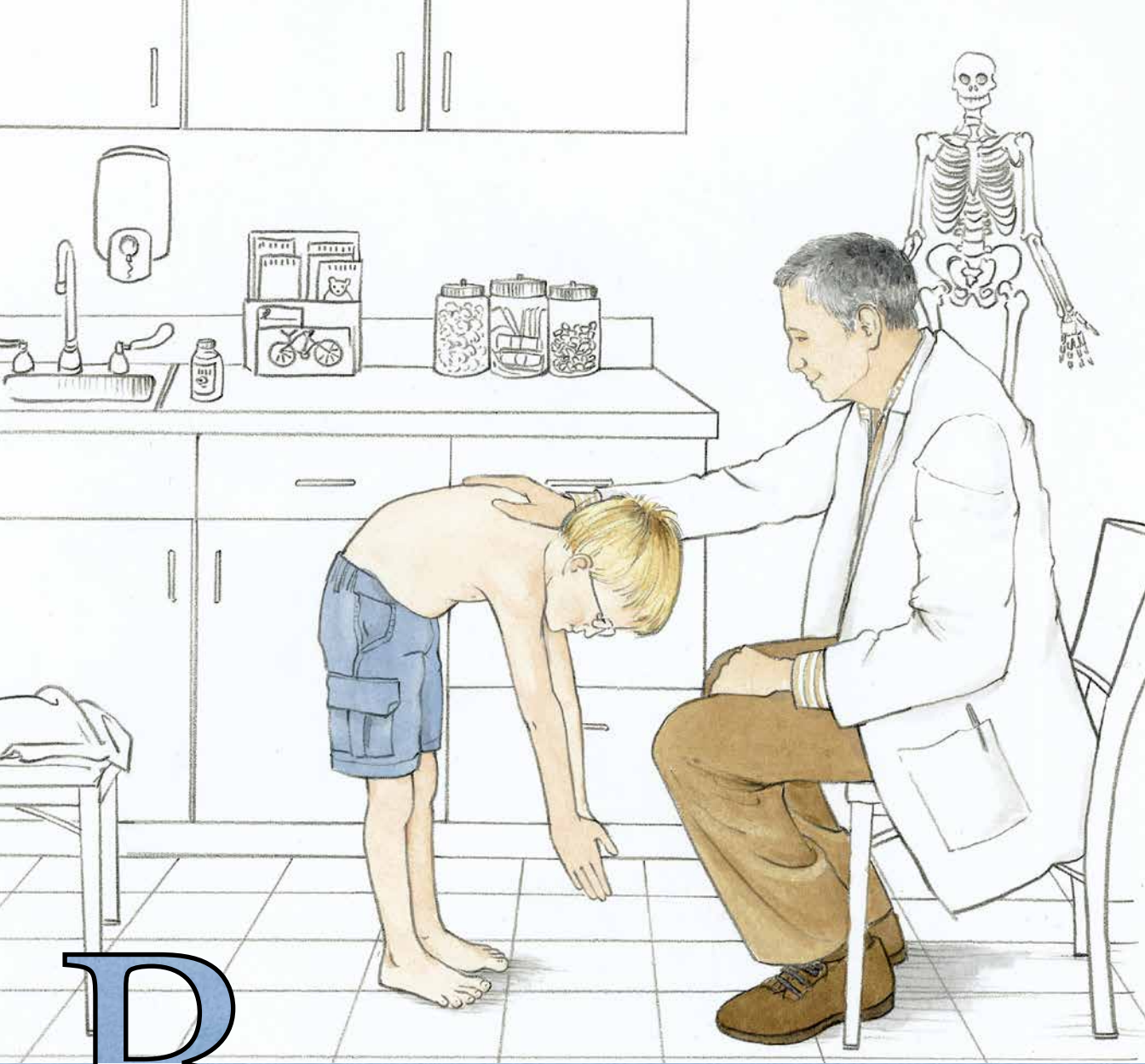
For further information about the  
Marfan Foundation or Marfan syndrome,  
please visit [www.marfan.org](http://www.marfan.org)  
or call (800) 8 – MARFAN.





A

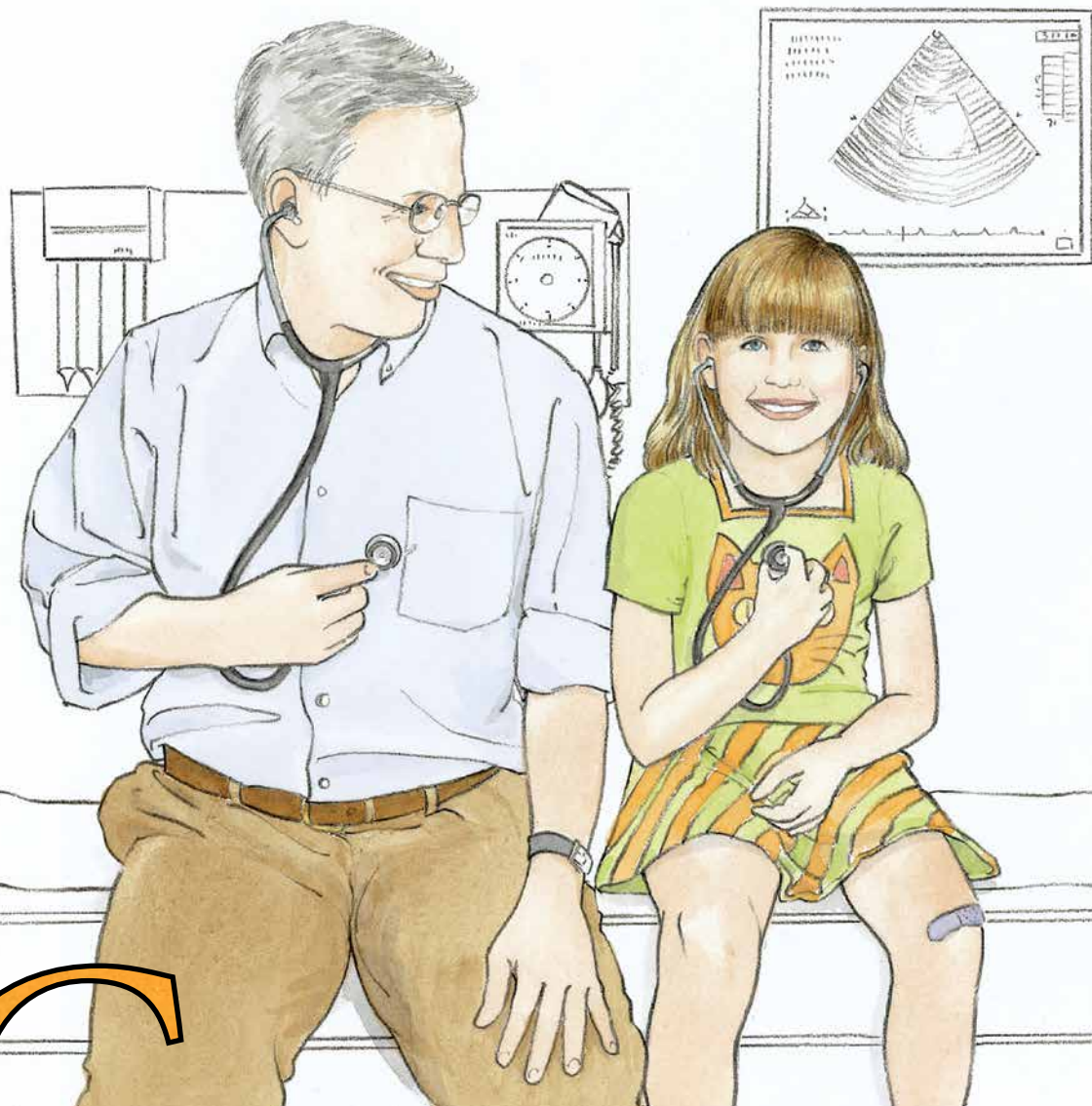
Anna's **aorta** is the largest **artery** in her body. It carries blood from her heart. She takes special medicine every day to keep her **aorta** from growing too big. What special medicines do you take?



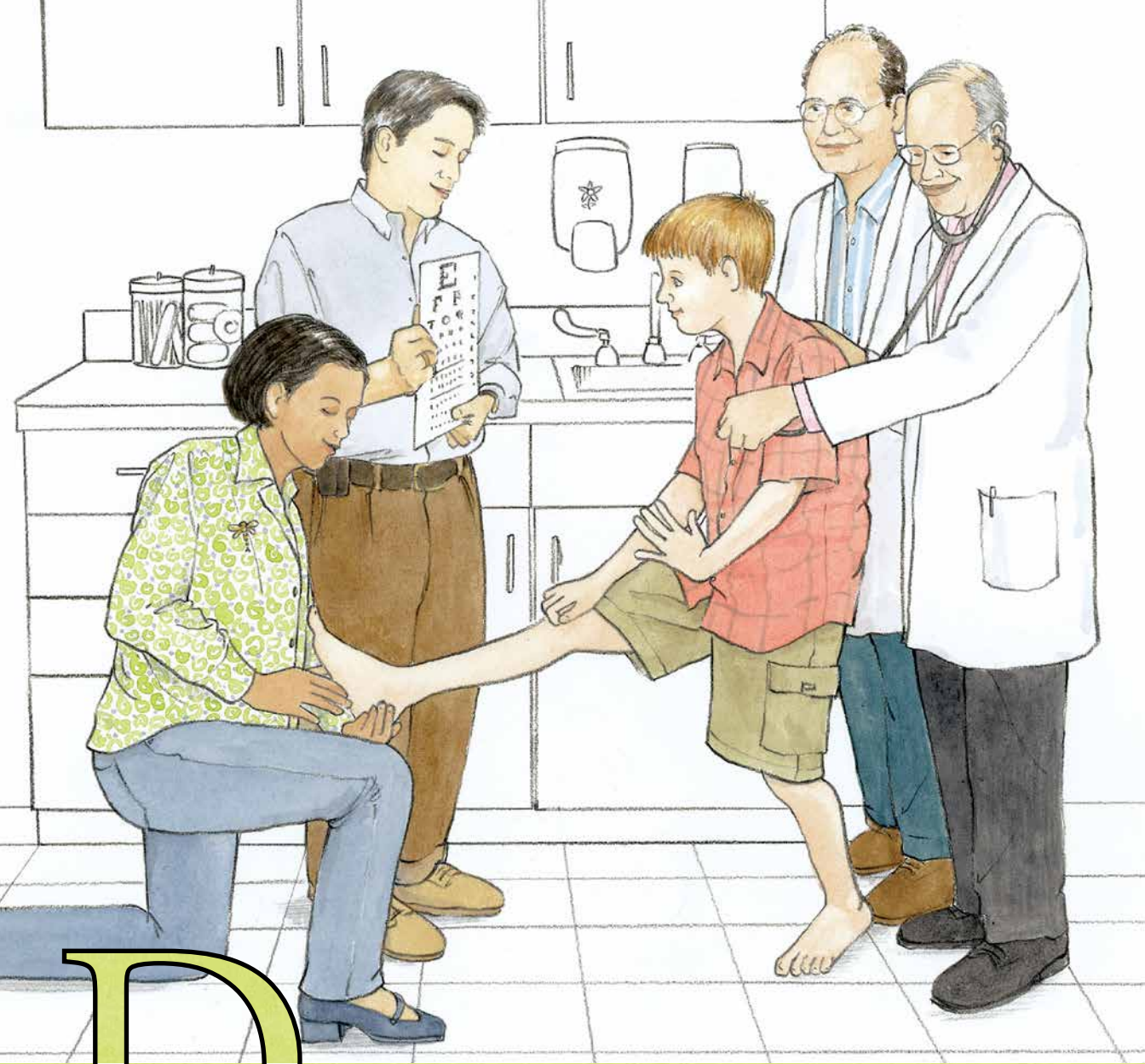
B

lake's back is curved. This is called scoliosis. Blake's orthopedist asks him to **bend** over and touch his toes so he can check the curve. Not everyone has a curved **back**. Do you?





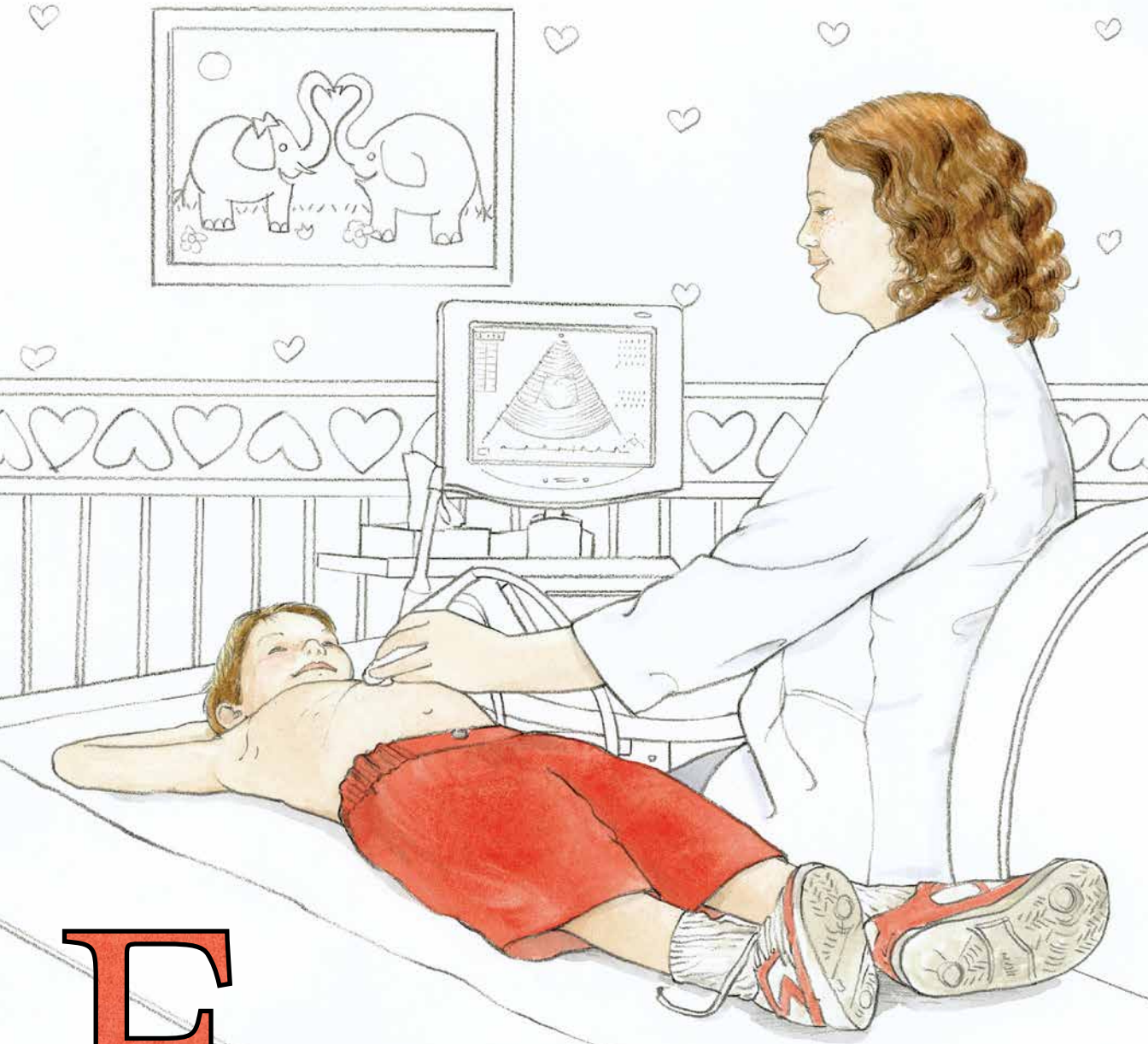
**C**ayla visits her **cardiologist** for regular **check-ups**. He listens to her heartbeat and looks at pictures of her aorta and heart valves. Sometimes **Cayla** listens, too!



D

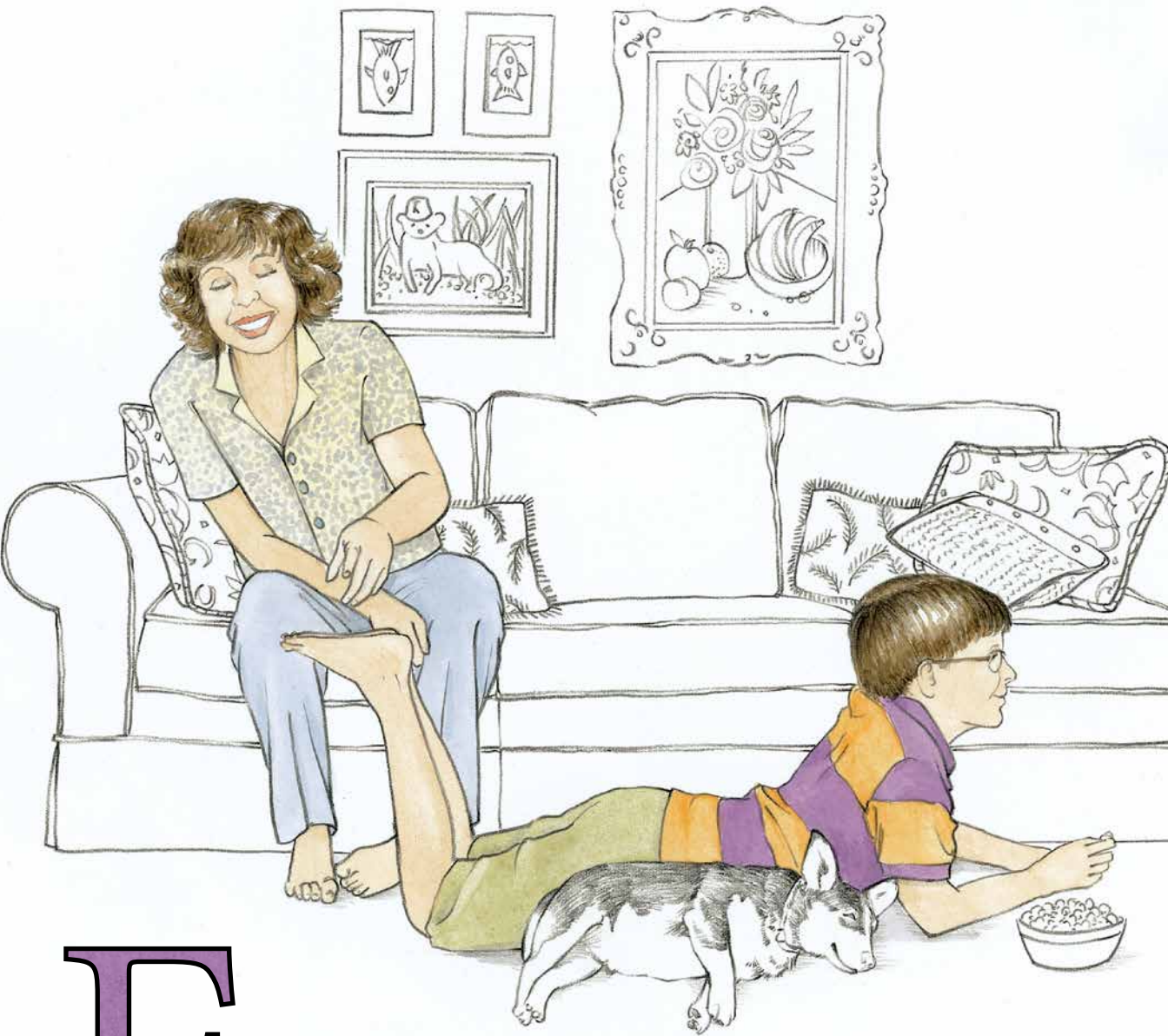
onovan has many **different doctors** who take good care of him. He sees a cardiologist for his heart, an ophthalmologist for his eyes, and an orthopedist for his back and feet. What **doctors do** you see?





**E**duardo gets an **echocardiogram** every year. First, the doctor uses a special jelly to make his skin slippery. Then she uses a wand called a transducer to take moving pictures of his heart. It doesn't hurt at all.





F

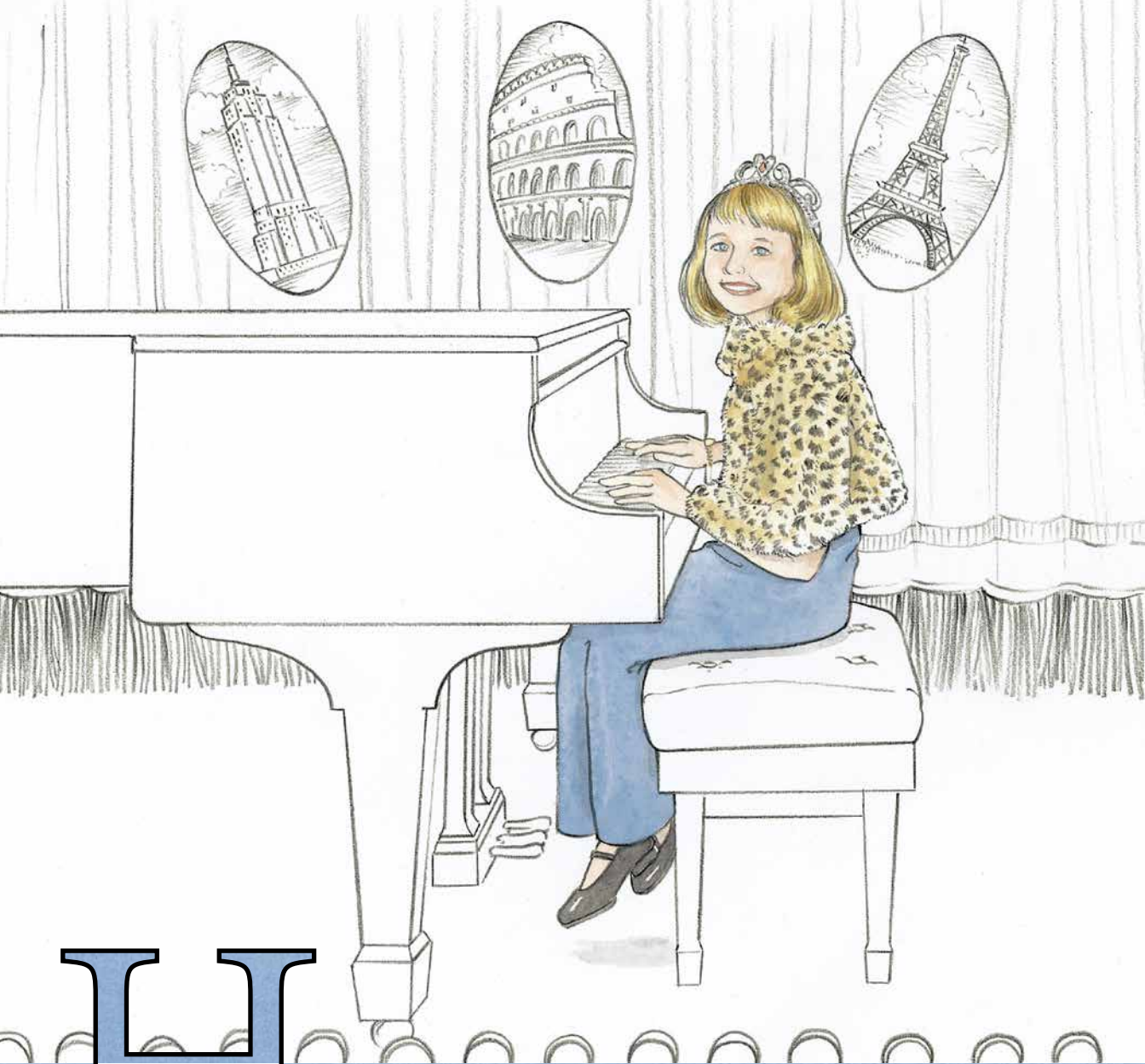
rankie has **flexible, flat feet**. His mommy says his long toes are beautiful. His grandma thinks they're super cute.



G

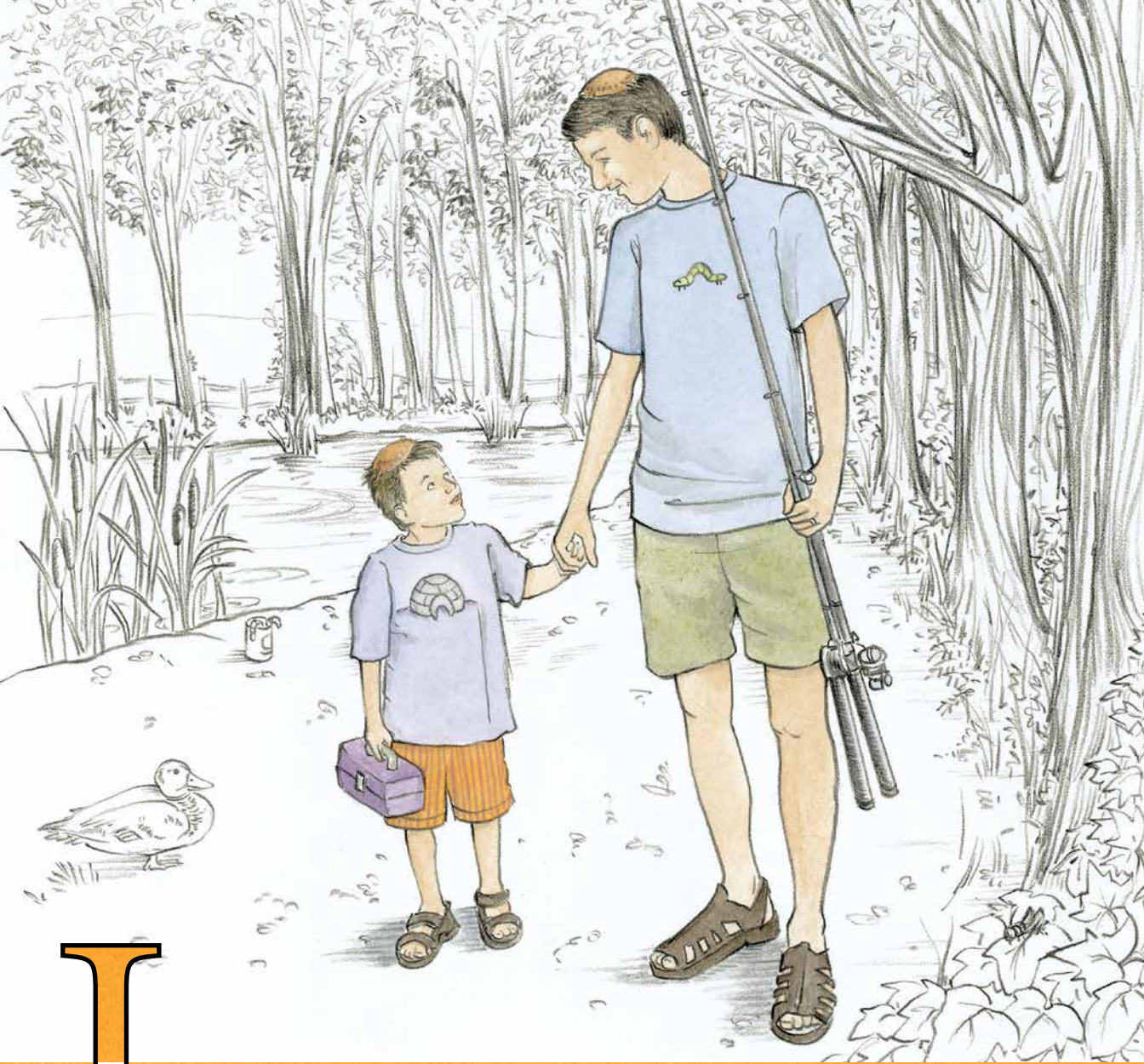
Gina's genes give her brown hair, green eyes, a great big smile and Marfan syndrome. To find out she has Marfan syndrome, a doctor measured her all over—from head to toe, from finger to finger!





H

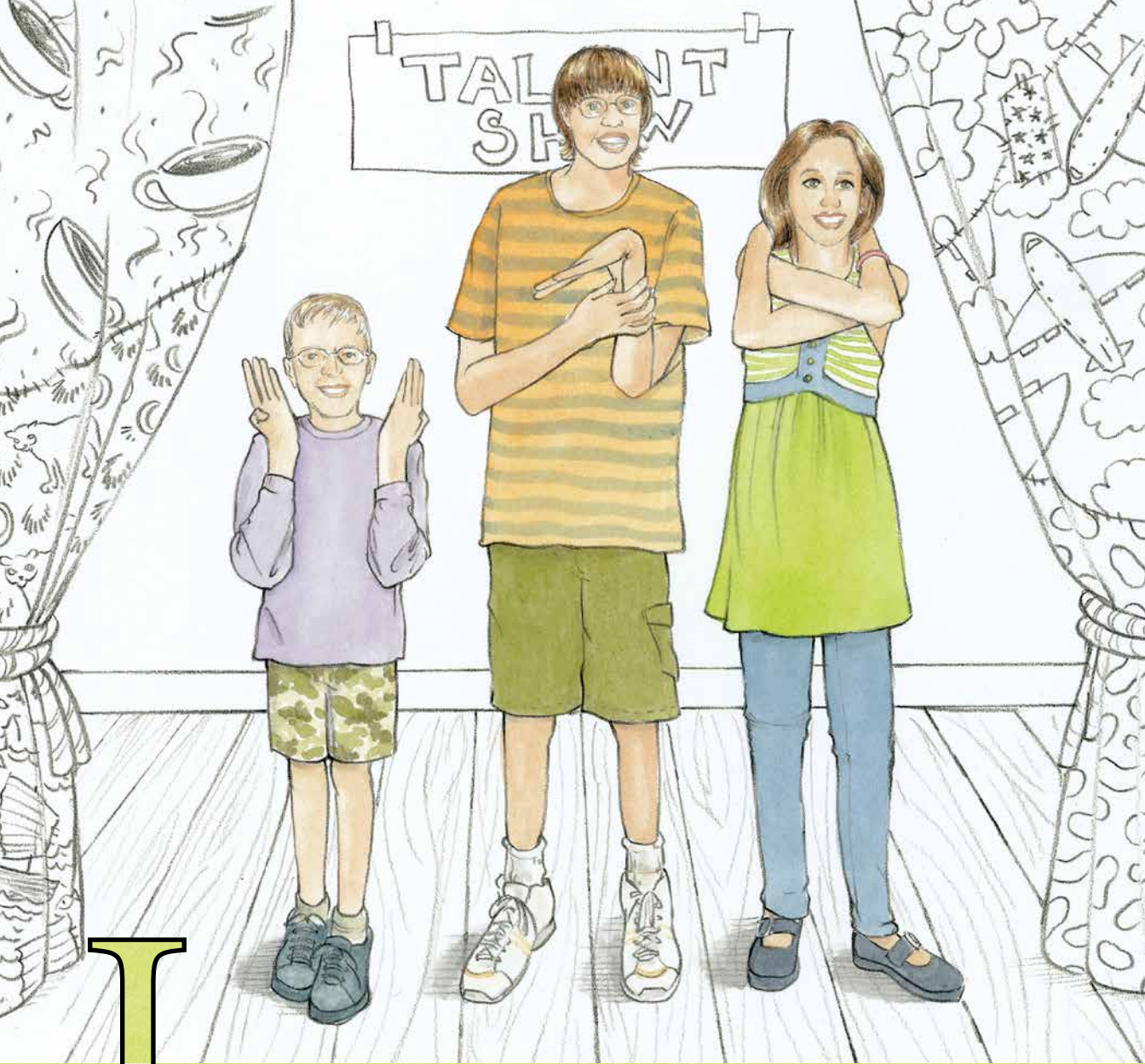
aley has **high hopes** for **her** future. She wants to be a concert pianist and travel the world. What do you want to be when you grow up?



I

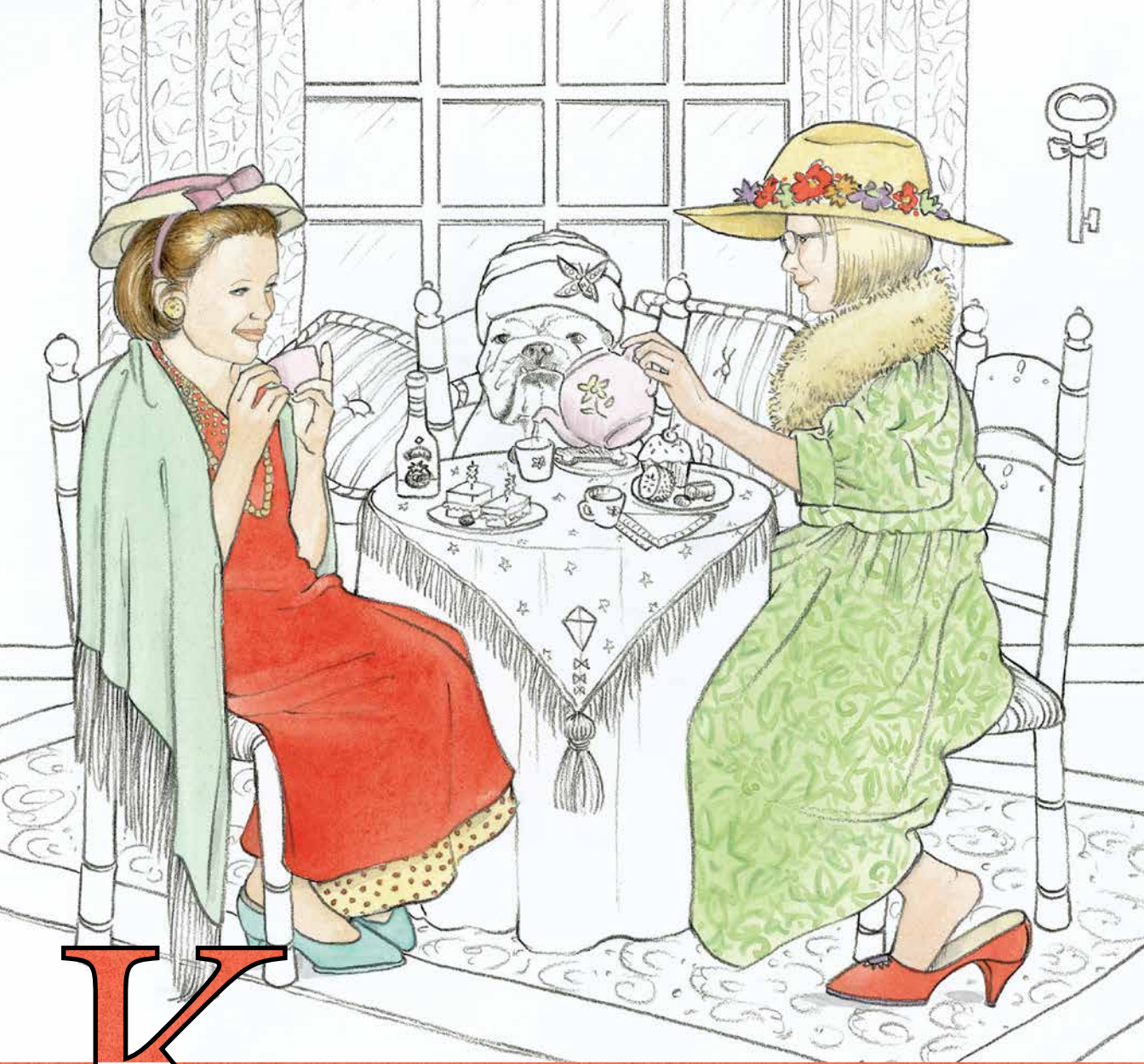
**saac inherited** Marfan syndrome from his dad, who has the condition, too. He talks to his dad when he gets worried or has questions. Who do you talk to?





**J**eff, Joe, and Julie have loose **joints** because of Marfan syndrome. They can do funny tricks that no one else can do, but they are always careful to take good care of their bodies.

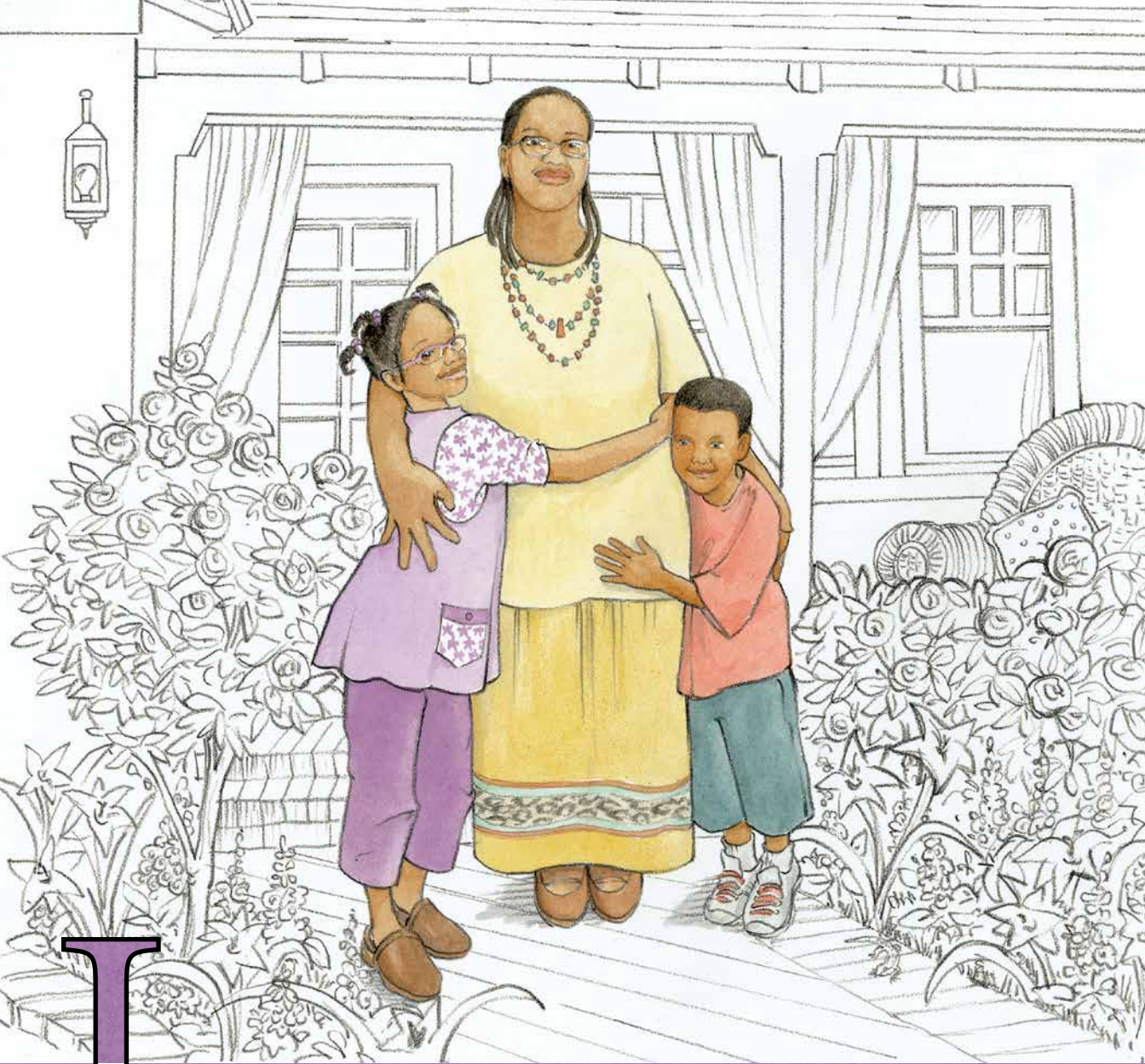




K

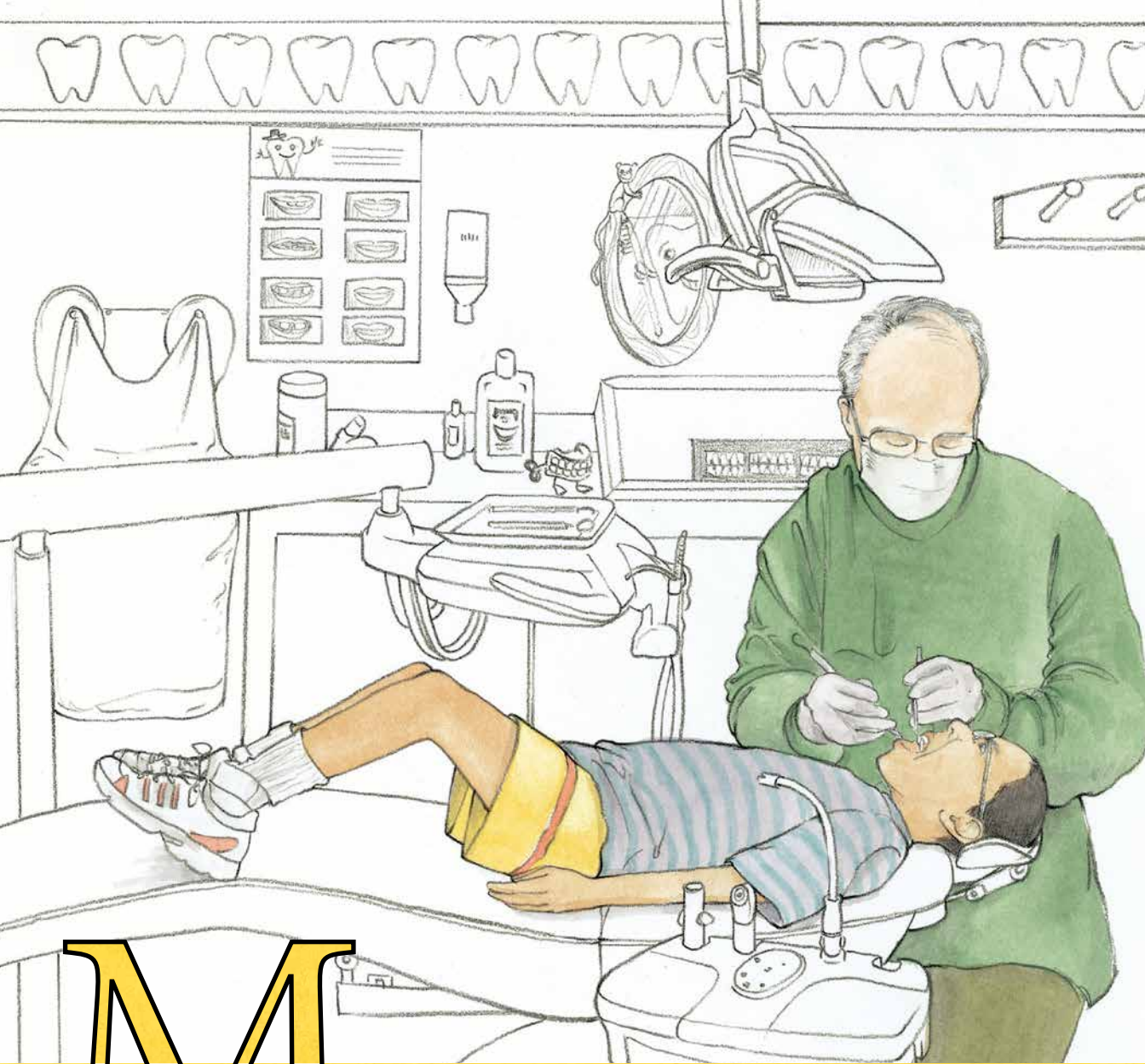
atherine's friend **Karen** is **kind** and knows Marfan syndrome makes her special. They like to play board games and make-believe. What games do you play with your friends?





**L**ucinda has long limbs. Her long legs help her ride a bike. And her long arms give the best hugs! Who do you like to hug?

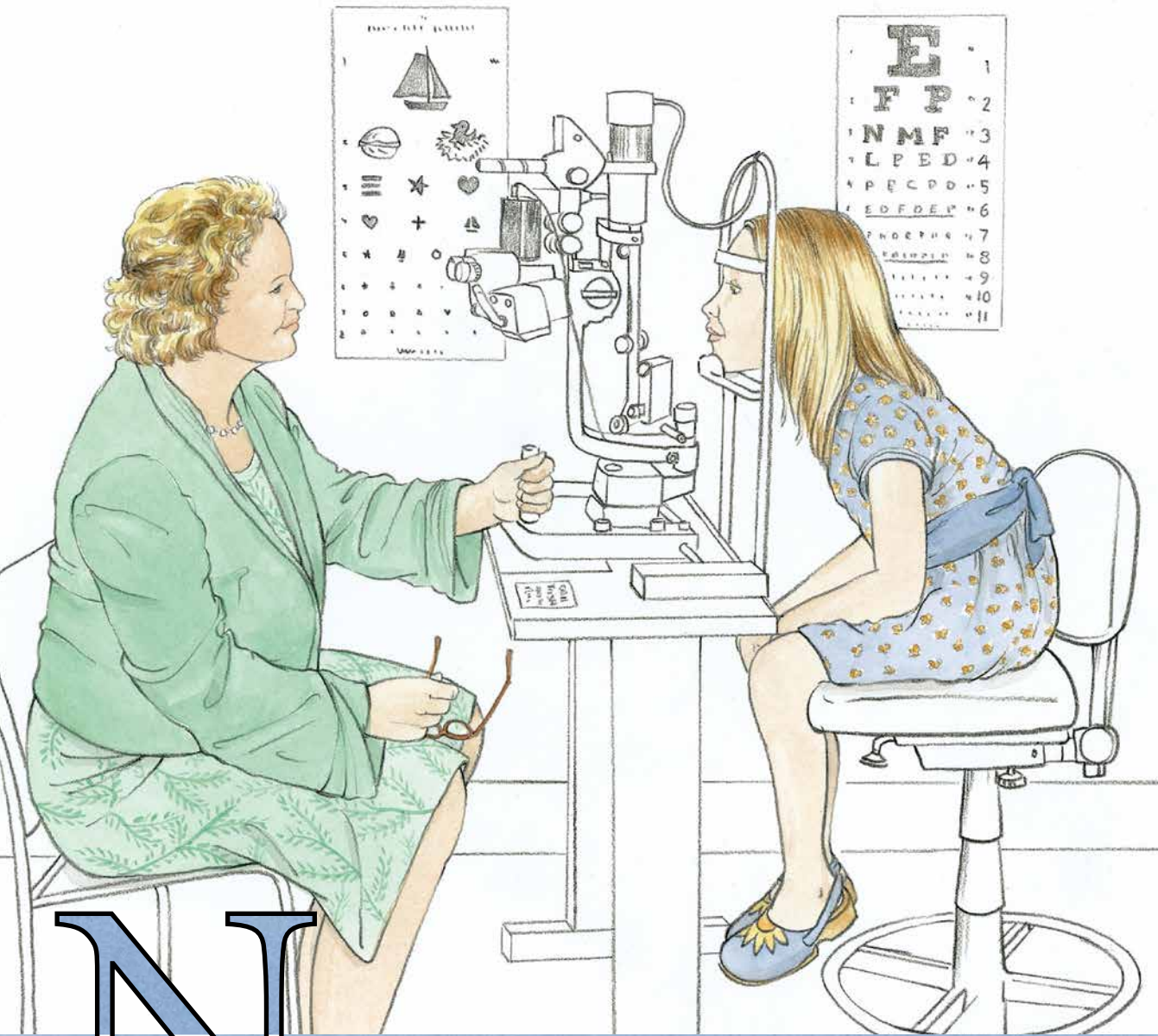




# M

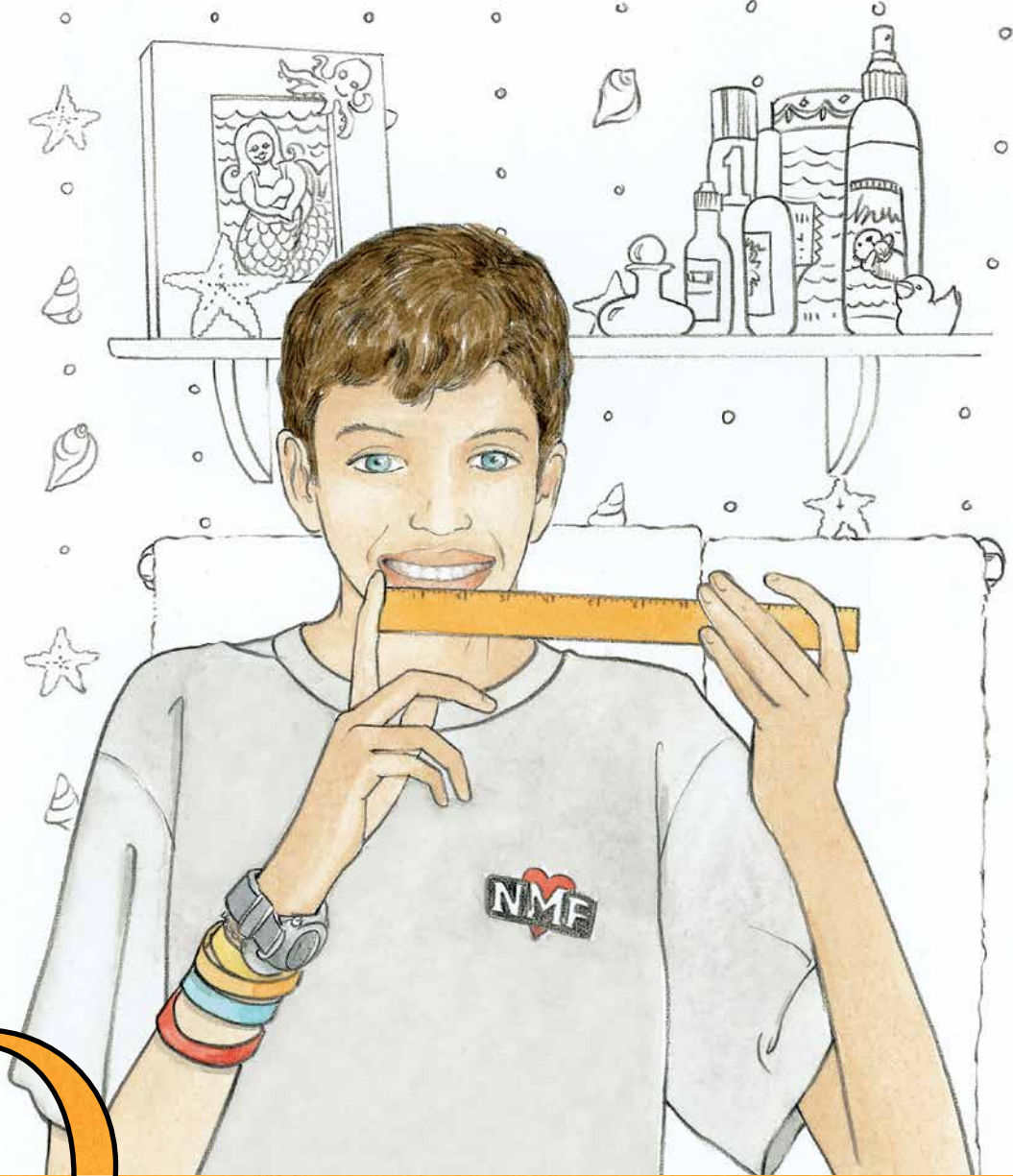
ark has a **mechanical** valve in his heart that his doctors gave him during an operation. Now he takes special **medicine** before he goes to the dentist to keep his heart healthy.





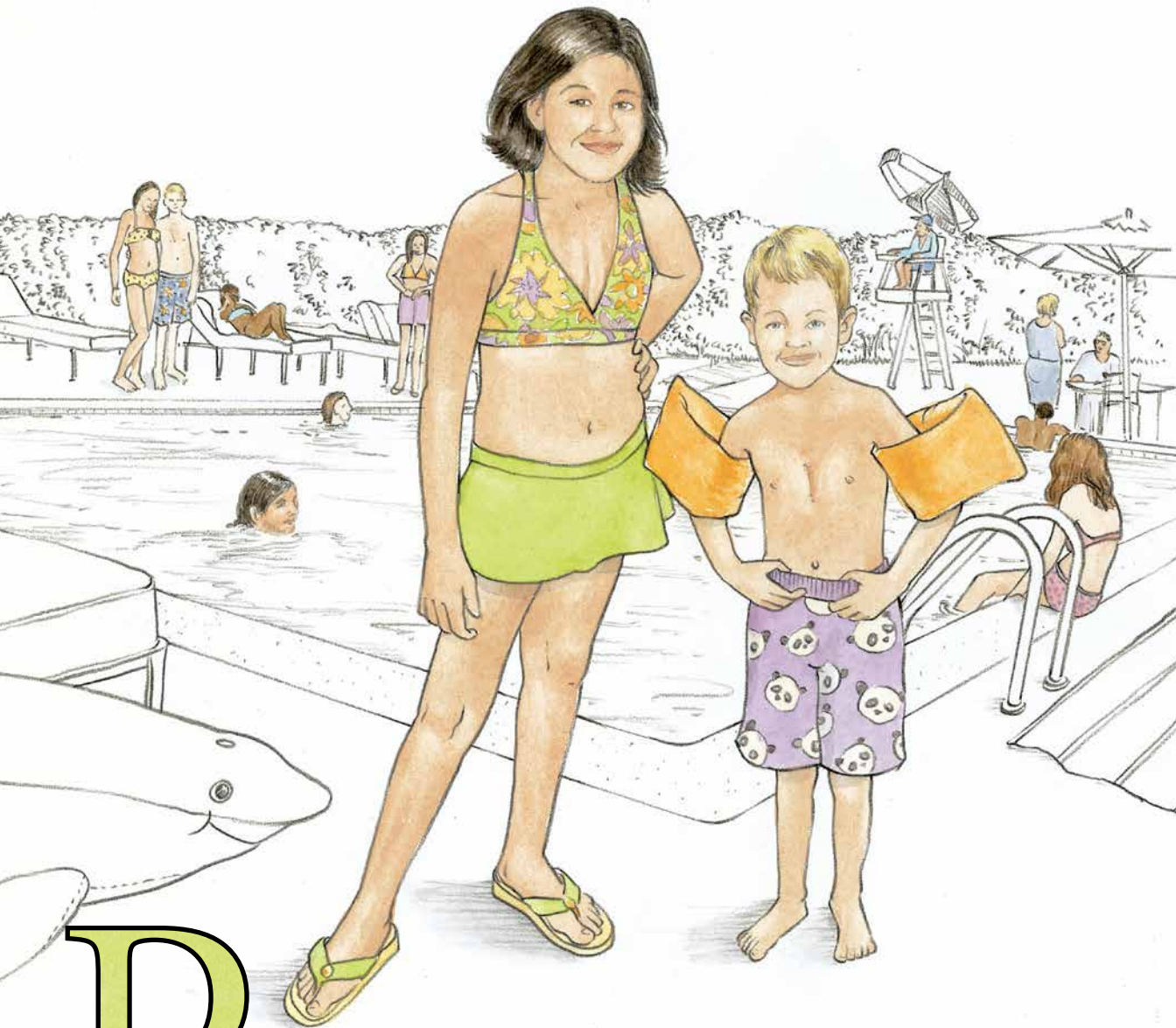
N

**adia** is **nearsighted**. She can see things up close, but things are fuzzy far away. This is called myopia. She wears glasses to help her see better.



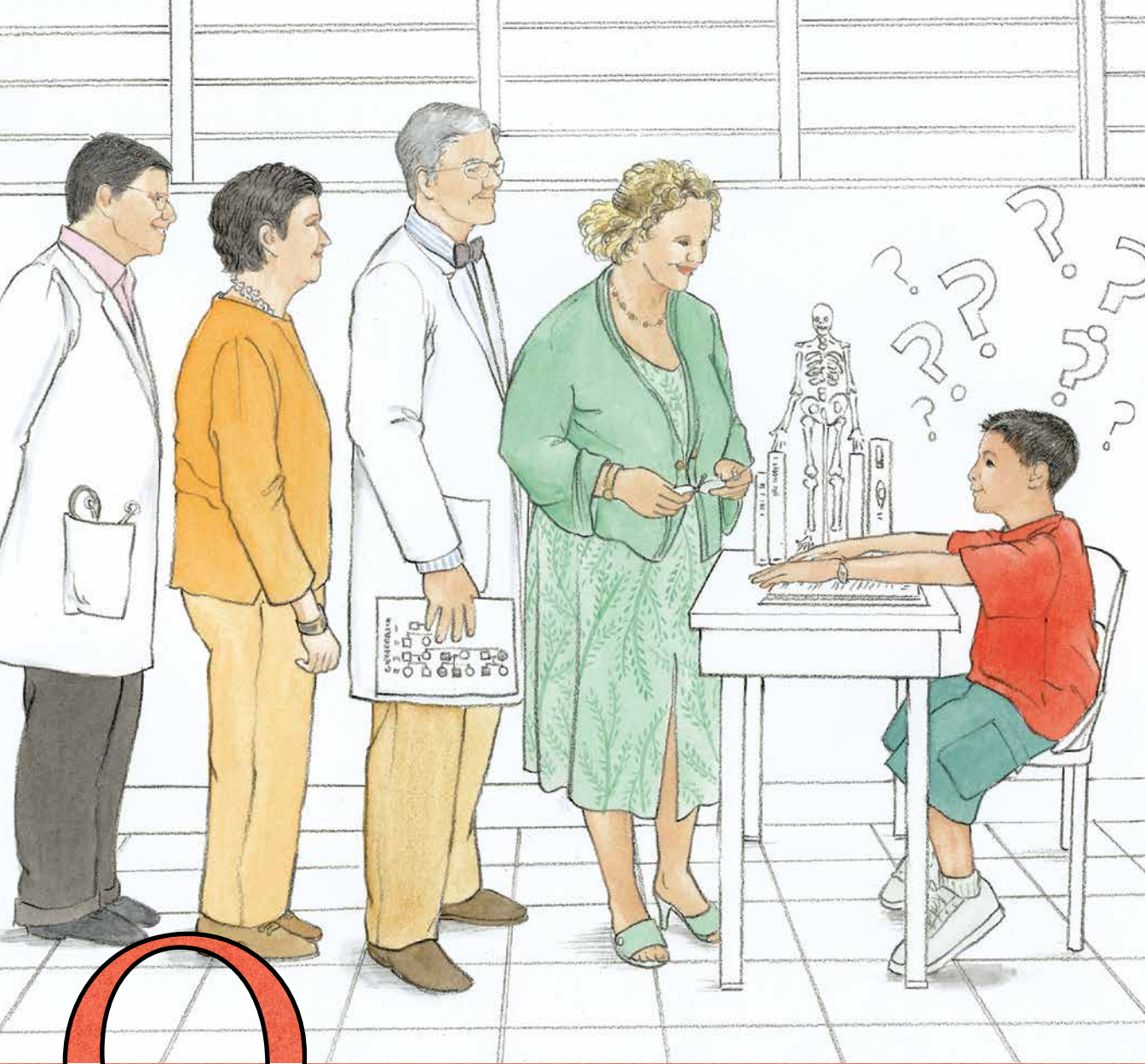
**Oliver's** orthodontist takes care of his teeth. He uses a palate expander to widen **Oliver's** mouth. When he is **older**, **Oliver** will get braces too. He has a big, beautiful smile. How big is your smile?





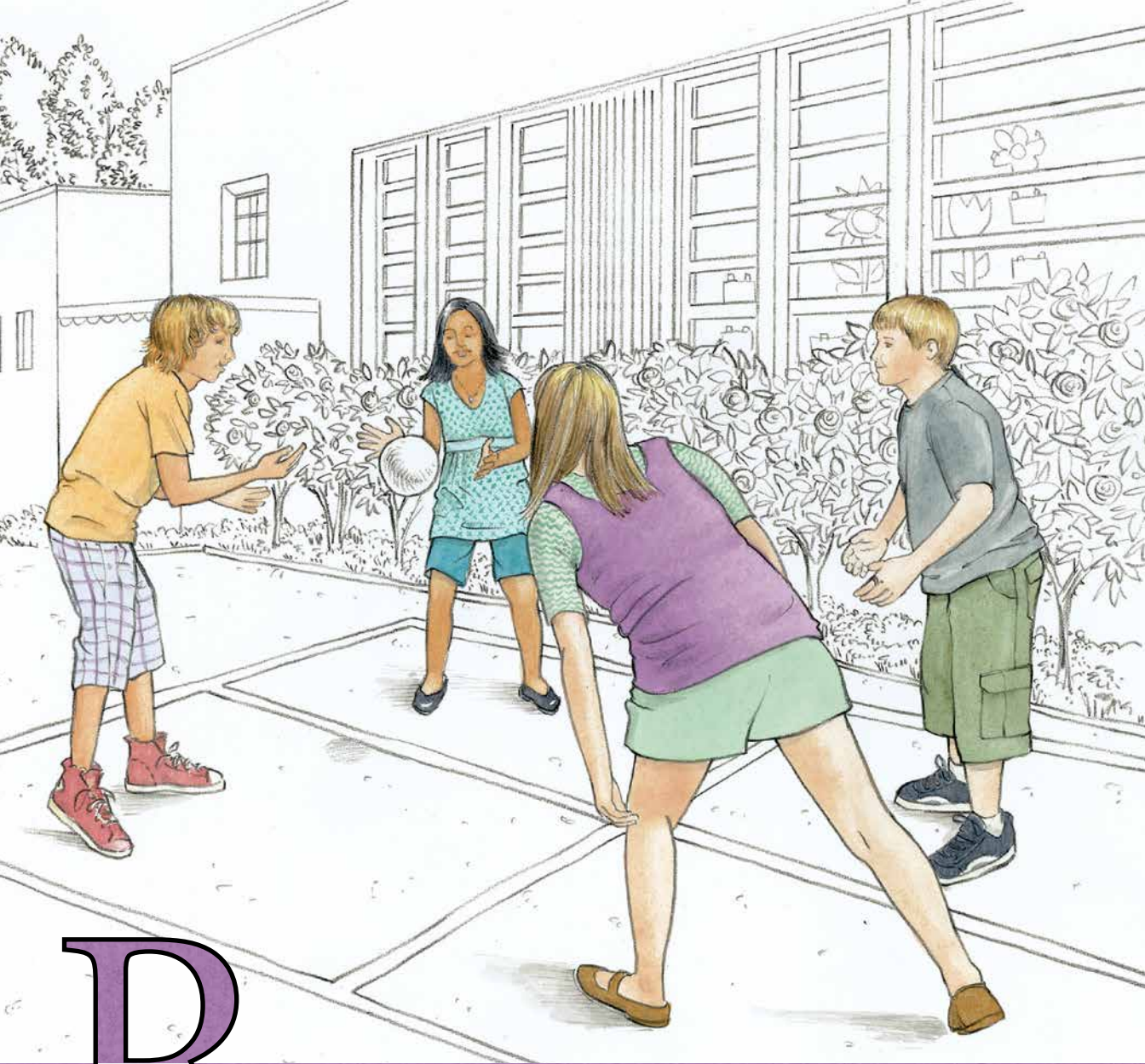
P

eter has **pectus excavatum** and **Priscilla** has **pectus carinatum**. **Peter's** chest bone dips in and **Priscilla's** sticks out. Everyone with Marfan syndrome is different!



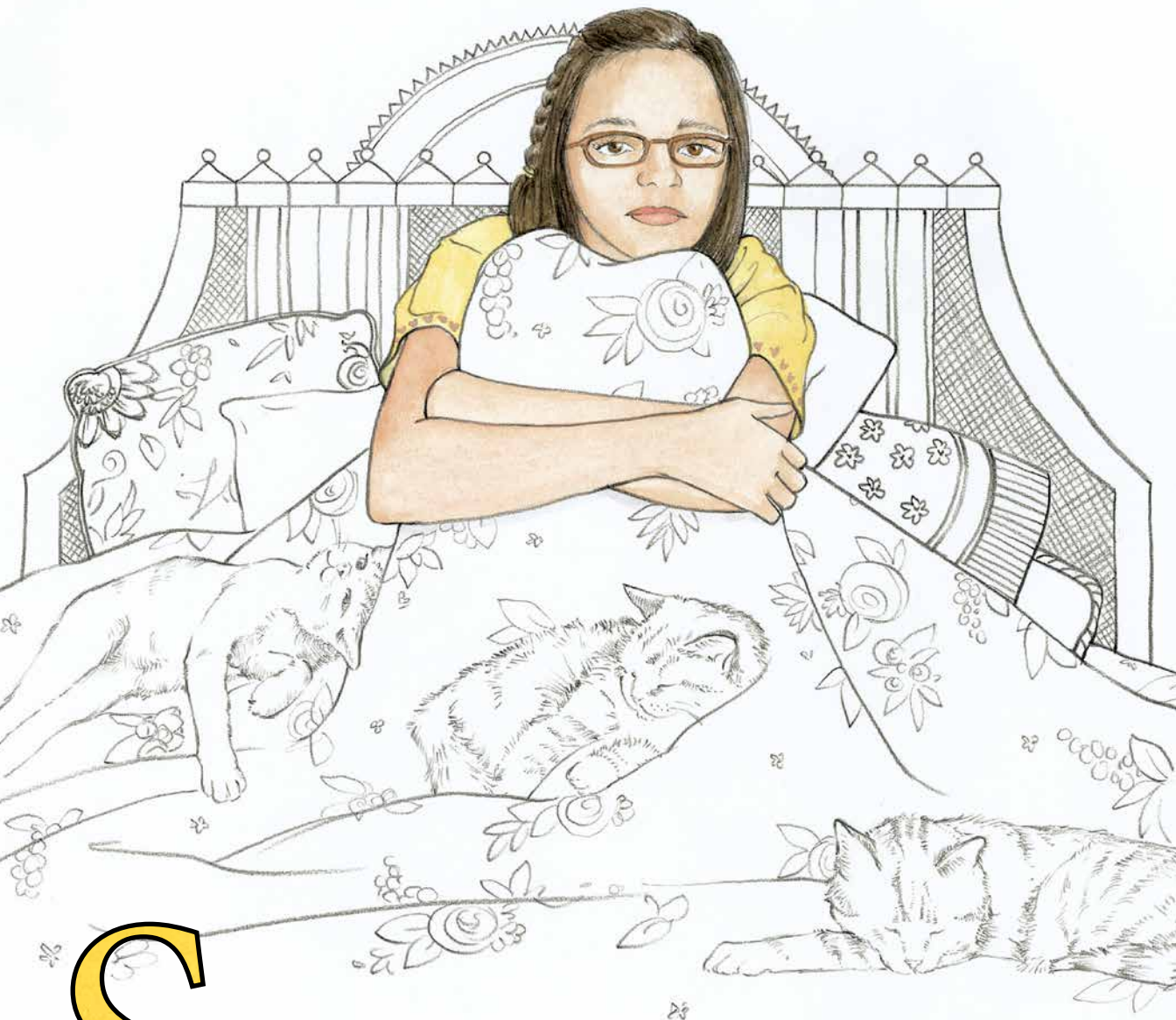
**Quinn** asks **questions** to learn more about Marfan syndrome. His doctors, parents, teachers and school nurse can all help him find the answers.





R

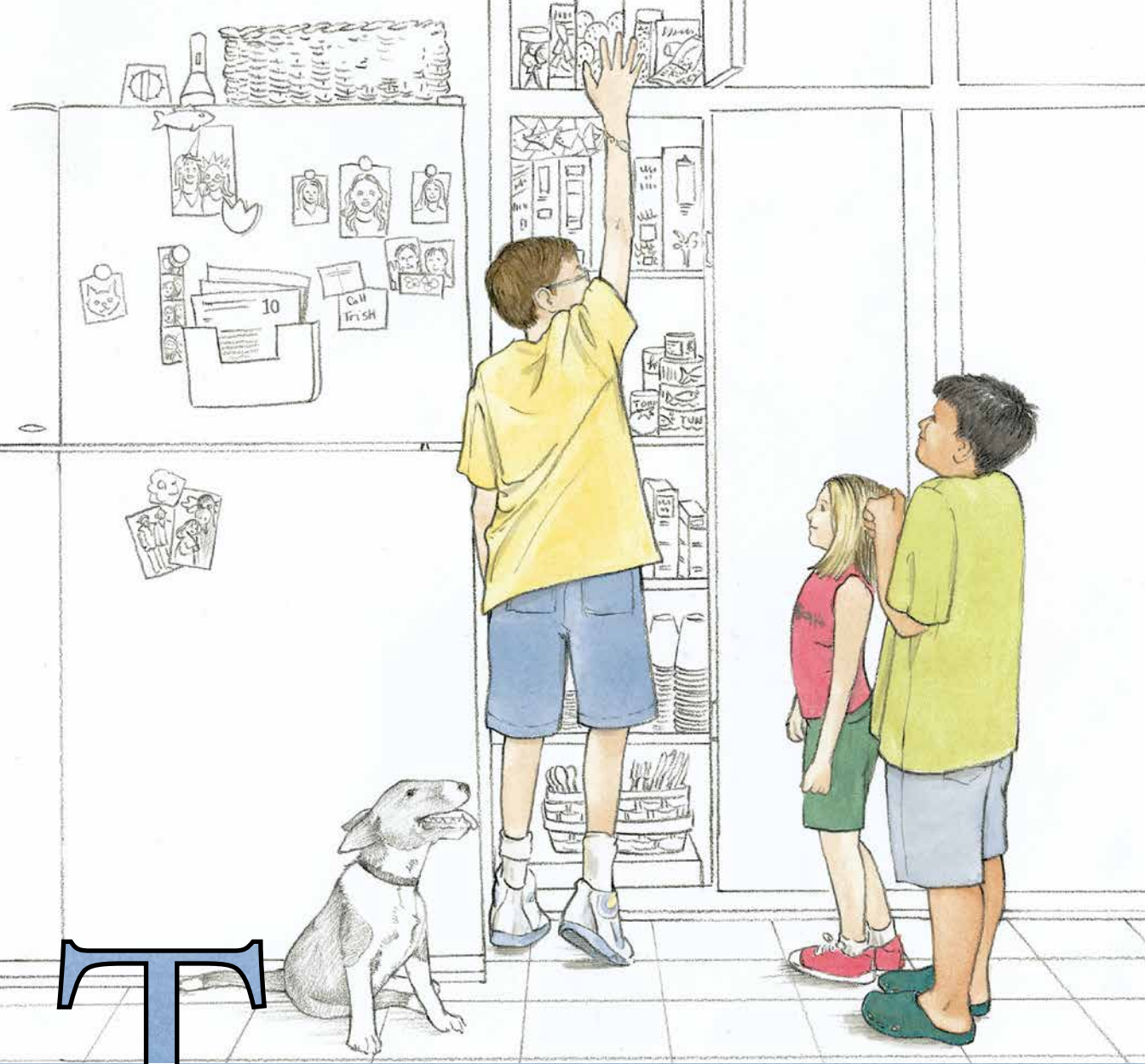
oberto really loves recess. He knows dodgeball isn't a safe choice, so he swings, slides and plays foursquare. What do you like to play at recess?



S

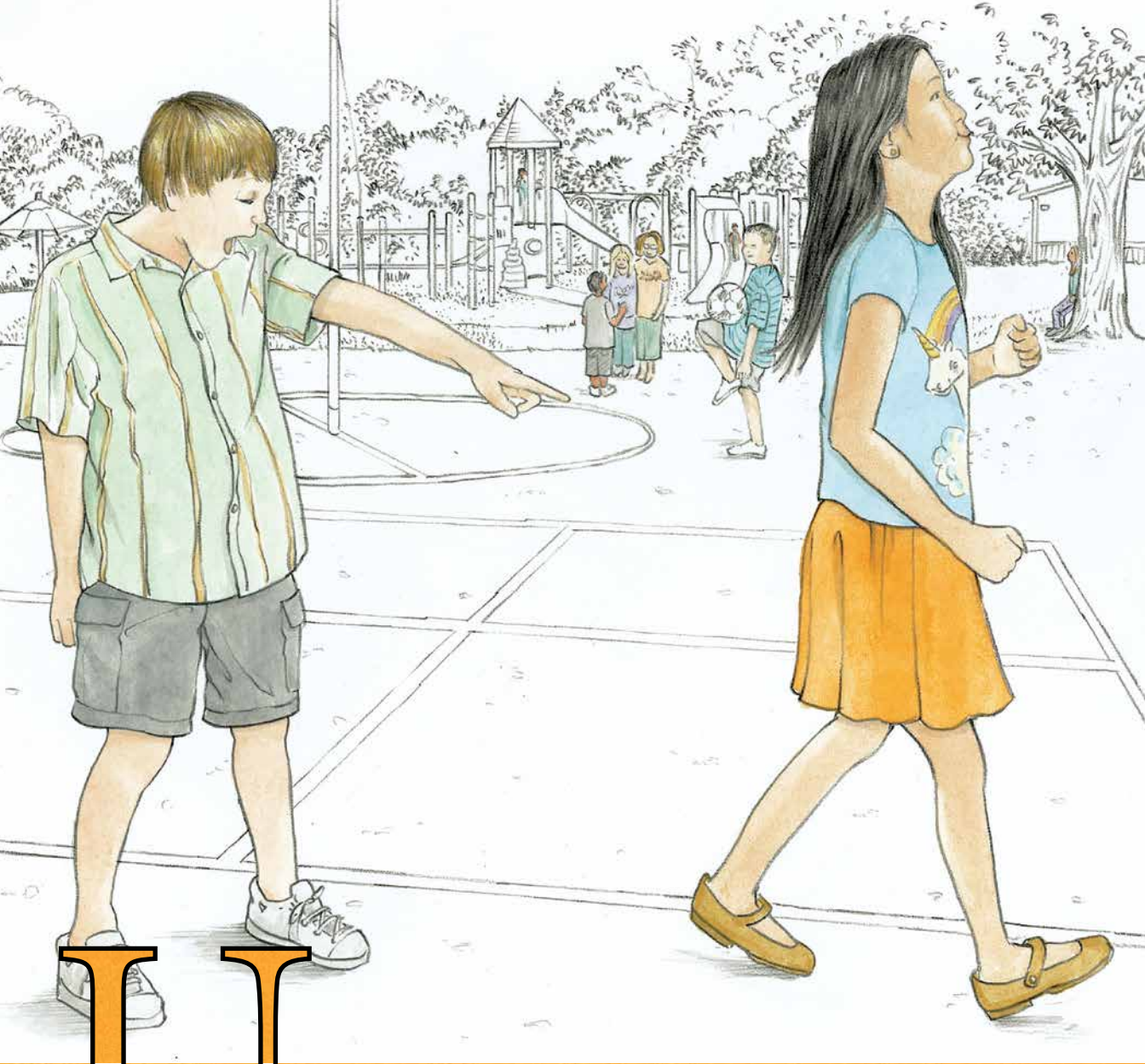
**sophie sometimes** feels **sad** because **she** has Marfan **syndrome**. What can you do to help her feel better?





T

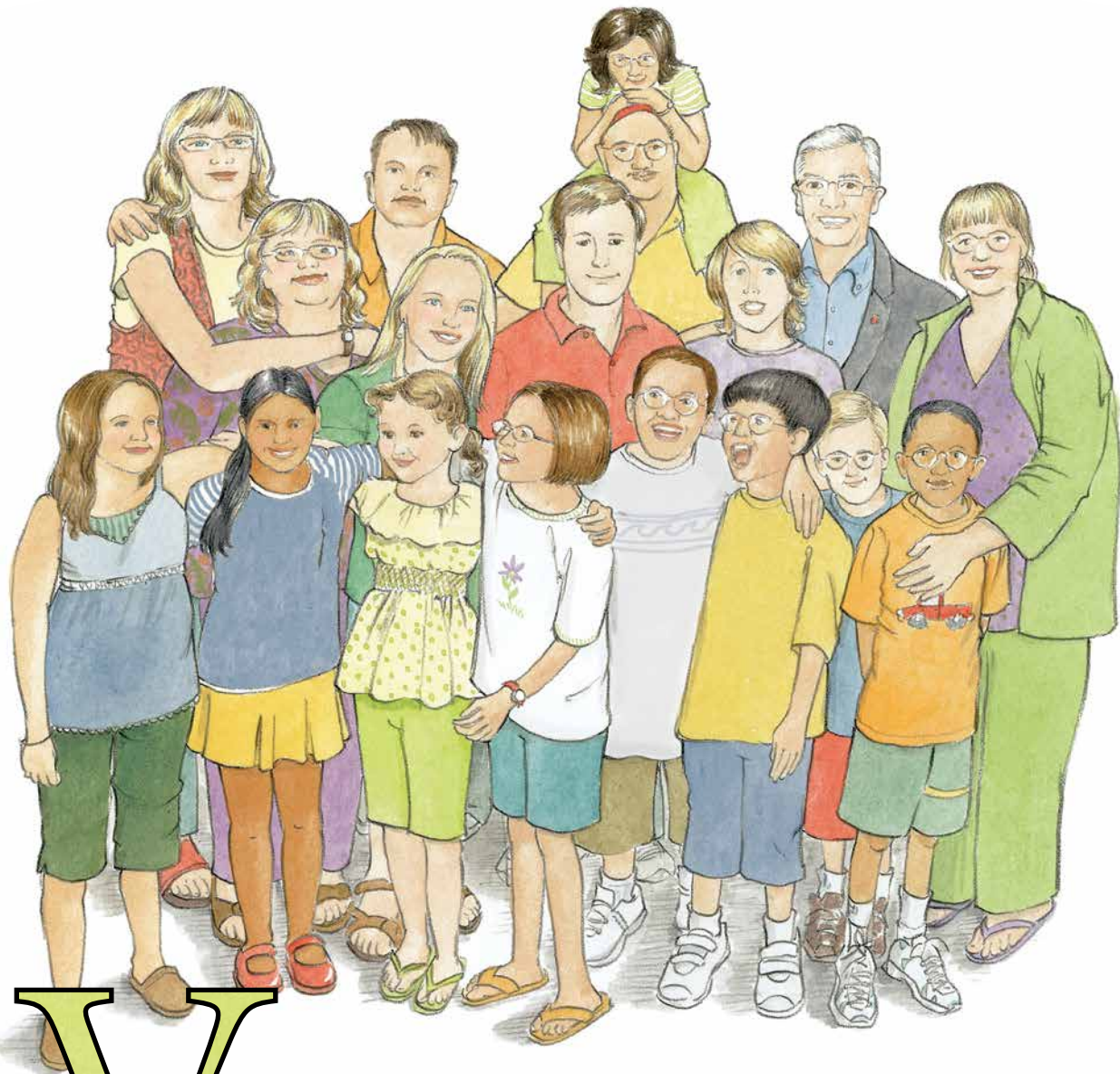
anner is **taller than** his friends and his older brother. He is proud to be **tall**. His friends like it because he can reach the cookie box.



U

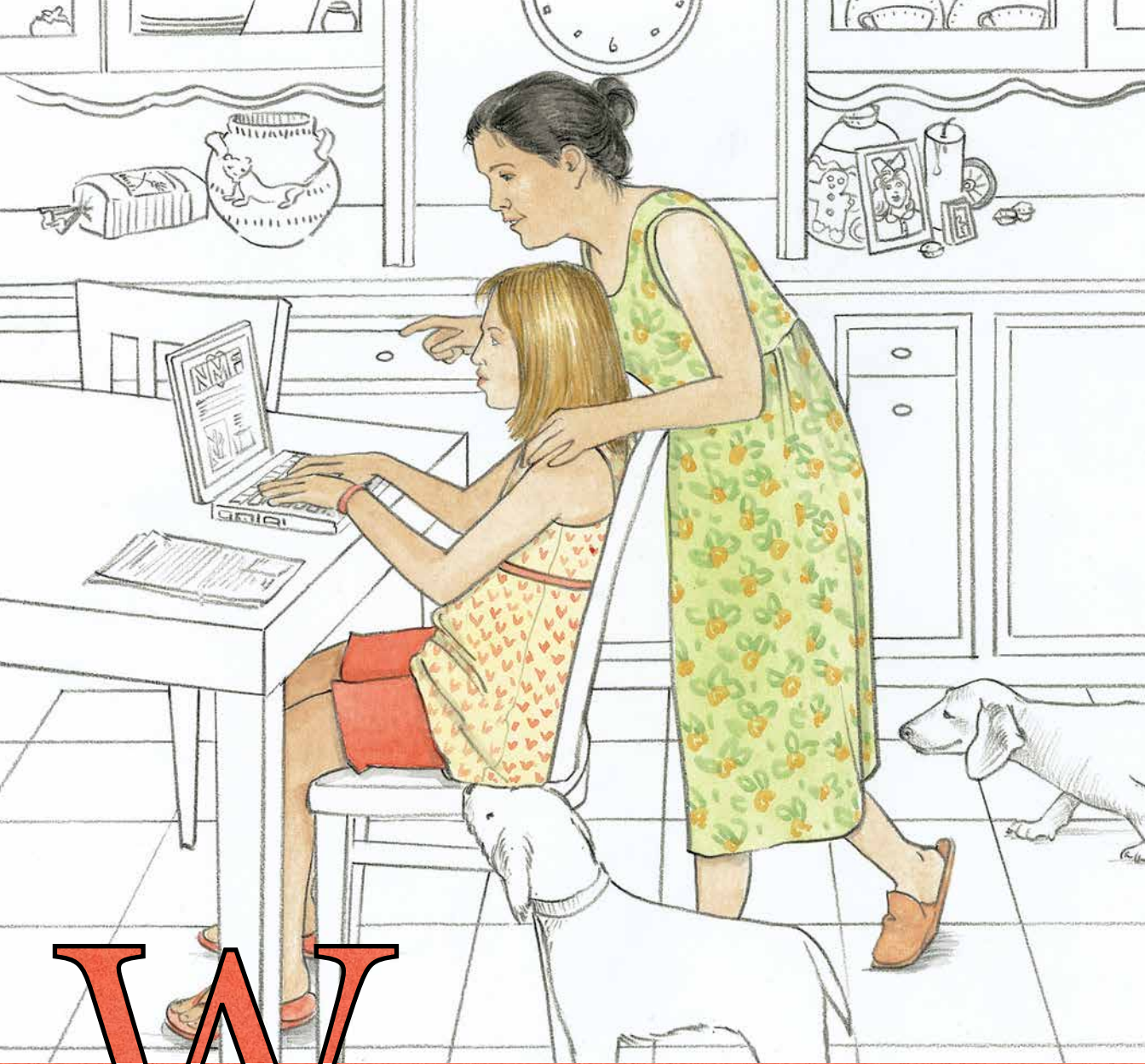
**meko understands** that teasing is **unacceptable**. When someone teases her, she walks away. She knows she can ask a grown-up for help. What would you do if you were teased?





V

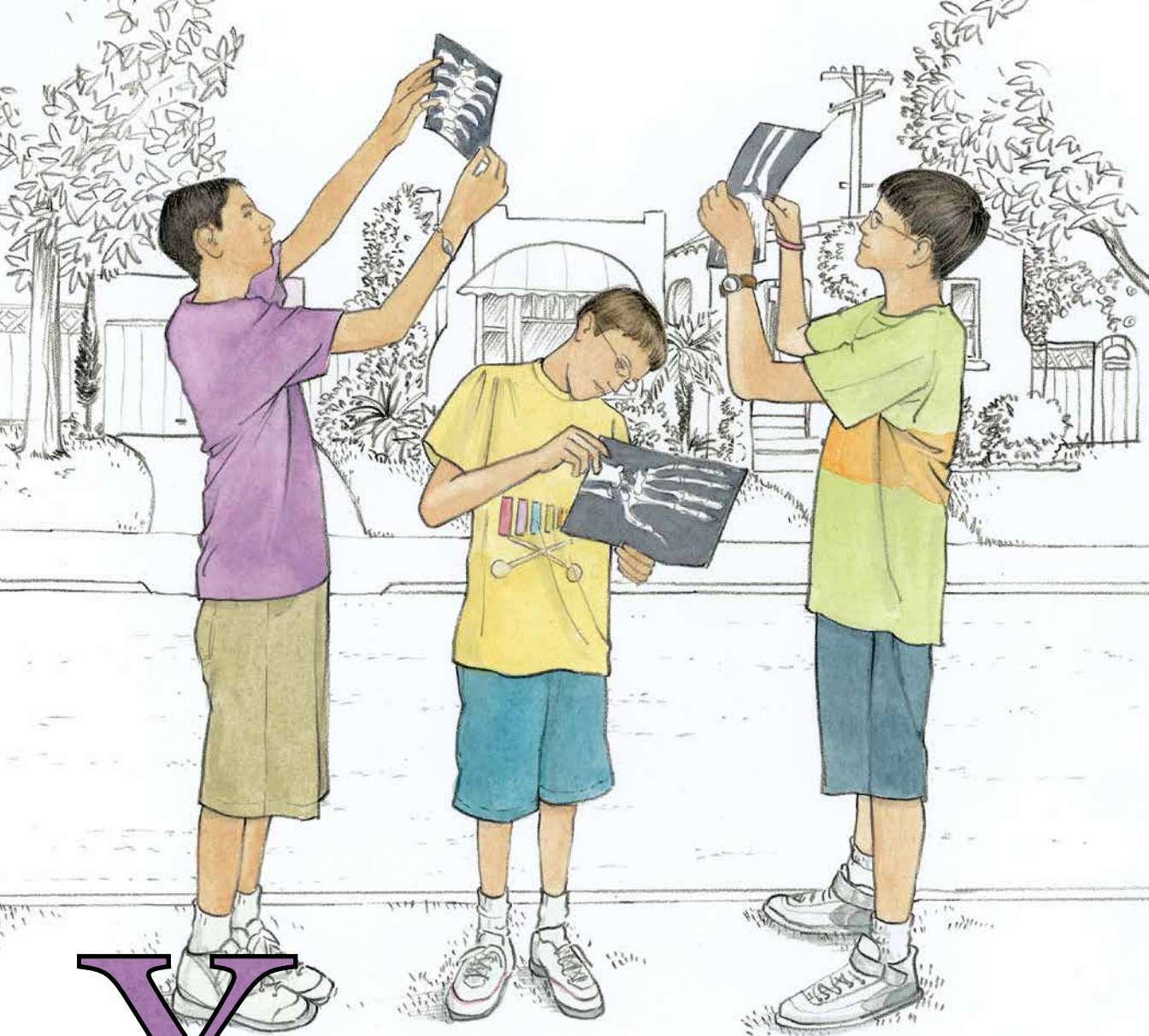
icki and her family **volunteer** for The Marfan Foundation.  
They meet really neat people and have a lot of fun.



W

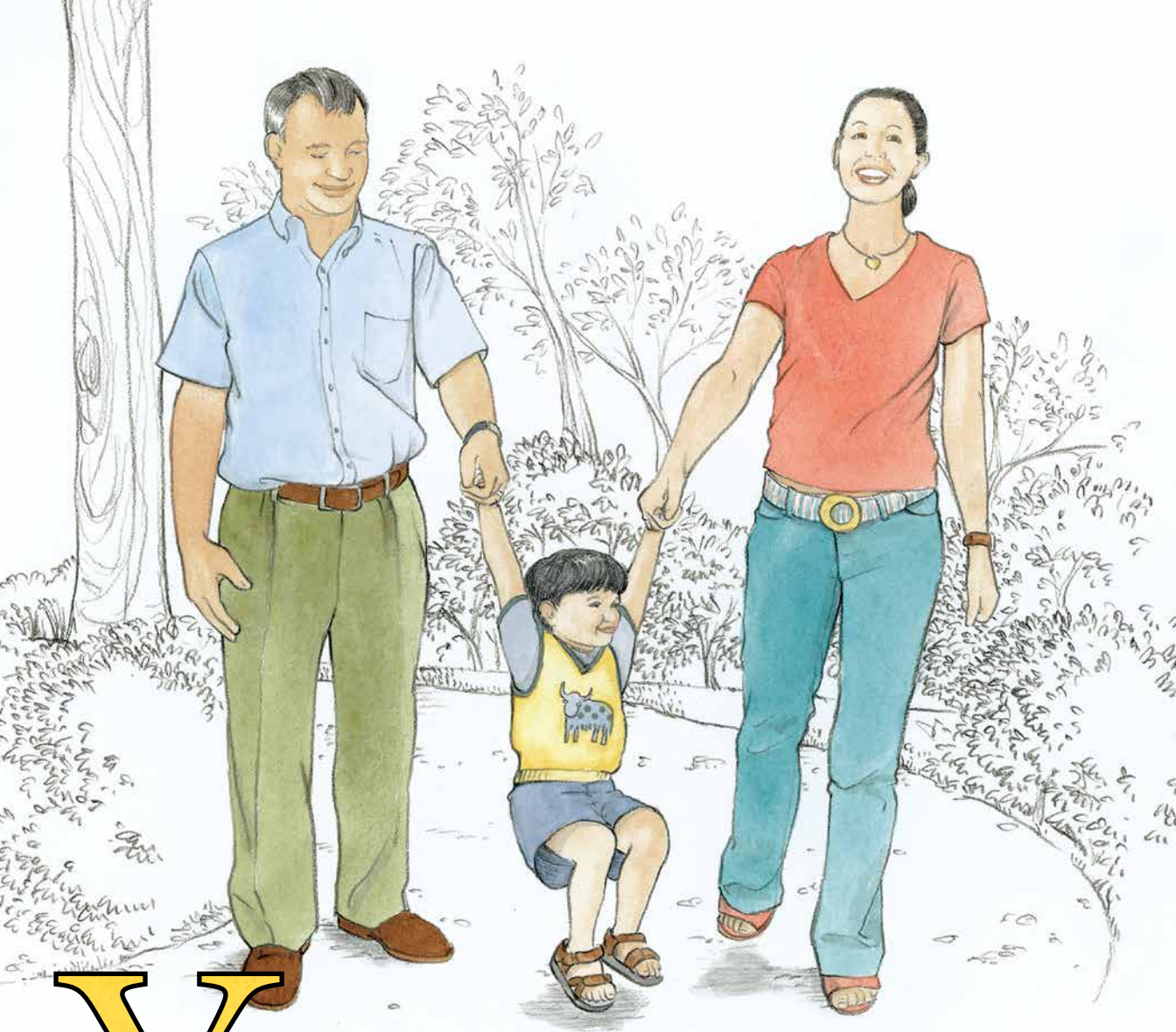
anda visits a lot of **wonderful websites**, especially **www.marfan.org**. It helps **Wanda** and her parents learn about Marfan syndrome and connect with other families.





X

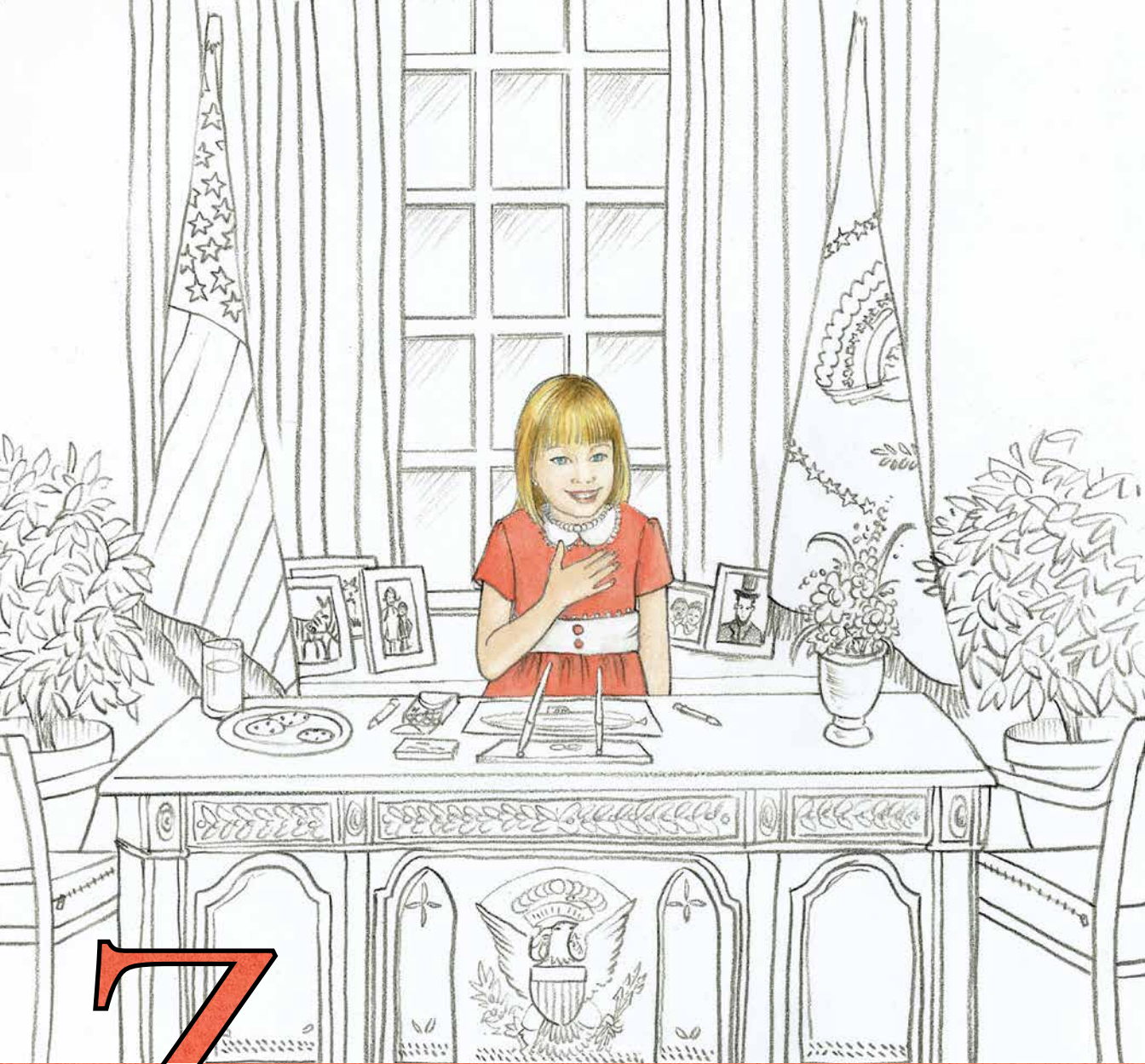
**xavier** loves showing his **x-rays** to his classmates. They show special pictures of his back, chest and mouth that help doctors see the bones inside his body. Have you ever had an **x-ray** taken?



Y

**amilito** was two **years** old when he was diagnosed with Marfan syndrome. Some people don't find out they have Marfan syndrome until they are much older.





Z

oeey has a **zest** for life! She loves her friends and family, and has big dreams for her future.



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FOUNDATION

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or Marfan syndrome,  
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(800) 8 – MARFAN.



# Glossary:

**Aorta** - The large artery that carries blood away from the heart to other parts of the body. Starting at the heart it is divided into: 1) aortic root, 2) ascending aorta, 3) aortic arch, 4) descending aorta.

**Artery** – A blood vessel that carries blood away from the heart to any part of the body.

**Cardiologist** – A medical doctor who specializes in the care of the heart.

**Echocardiogram** – A painless test that uses sound waves to take pictures of the heart and the blood vessels close to the heart.

**Genes** - Tiny parts of each cell passed from parents to their children that tell the body how to grow and function.

**Geneticist** – A medical doctor who specializes in genetic disorders (disorders that are caused by changes in the genes).

**Heart** – The organ that keeps blood flowing throughout the body.

**Heart valve** - A part of the heart that opens and closes with each heartbeat. Our hearts have four valves that work together to help keep blood flowing through the heart and body.

**Inherit** – When a person receives a feature from a parent through the genes. The feature can be how a person looks or, as with Marfan syndrome, can be a genetic disorder.

**Joints** – Where two bones are joined together to allow the bones to move. For example, elbows, knees, ankles and shoulders are all joints in our body.

**Mitral valve prolapse (MVP)** – When the mitral valve (one of the four valves in the heart) has extra tissue and is “floppy.” The extra tissue can cause a heart murmur (a sound the doctor can hear) and the valve to leak.

# Glossary:

**Marfan syndrome** – A genetic disorder of connective tissue caused by a mutation (change) on the gene that tells the body how to make a protein called fibrillin-1.

**Ophthalmologist** – A medical doctor who specializes in care of the eyes.

**Orthodontist** – A dentist who specializes in preventing and fixing crowded teeth and other problems of the teeth and jaws. They often use braces and other dental appliances.

**Orthopedist** – A medical doctor who specializes in the care of the bones and joints.

**Palate expander** – A special device the orthodontist puts on the roof of the mouth that will make the upper jaw wider over time. Once the jaw is wider, the orthodontist takes out the palate expander.

**Pectus carinatum** – When the sternum (chest bone) protrudes or sticks out. It is sometimes called “pigeon breast.”

**Pectus excavatum** – When the chest is indented or sinks in. It is sometimes called “funnel chest.”

**Scoliosis** – When the spine curves to one side. About 6 in 10 people with Marfan syndrome have scoliosis.

**Transducer** – The device that sends painless sound waves into the body and back to make the pictures produced in an echocardiogram.

**X-ray** – Pictures of the inside of the body made by a special energy beam. Getting an x-ray does not hurt. X-rays are often pictures of the bones and teeth.



## **Did you notice all the hidden pictures within the illustrations?**

Airplane, accordion, armadillo, artichoke, anvil, apple, alligator,  
amethyst, adult, asterisk  
Bones, bandaids, bicycle, bear, balloon, bottle, blue, brown, blonde boy,  
back, basin  
Cardiologist, cuff, cat, cut, circle  
Donuts, depressors, daisy, dispenser, doctors, drawers, dragonfly  
Elephants, echocardiogram, elbow, eyes, elastic waistband  
Flowers, fruit, frames, fish, ferret in a fez, feathers, fingers, feet, fur, furniture  
Girl, garden, green, giraffe, glasses, gladiolas, gecko  
Hair, head, heart, human  
Igloo, inch worm, ivy, insect  
Jet, java, joints, jaguar, jellybeans, jigsaw puzzle  
Key, ketchup, kite, kids, kiwi fruit  
Light, lanai, lilies, lady, little boy, leopard print, lizard  
Mouth, monkey, man, molars, machines, mirror, mask  
Necklace, nest, nut, notecard, numbers  
Octopus, orange, ocean, one  
Pandas, purple, pool, petals  
Question marks  
Red shoes, roses, rubber ball, ring  
Sunflower, snail, sleeping cats  
Timer, tulip, tortilla chips, tomato, tuna, note to Trish  
Unicorn, umbrella  
Volunteers, vegetables, velcro® (on shoes)  
Woman, weiner dog, website, walnuts, weasel, wick, white  
X-rays, xylophone  
Yellow sweater, yak  
Zebra, zippers, zinnias

**Visit The Marfan Foundation website at [www.marfan.org](http://www.marfan.org)  
to download pictures from this book that you can color yourself!**

# Acknowledgments:

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This book has been made possible by a generous grant from the

**American Legion**  
**Child Welfare Foundation**



For more information on  
this worthy organization,  
please visit their website at  
[www.cwf-inc.org](http://www.cwf-inc.org)

For further information about The Marfan Foundation or Marfan syndrome, please visit  
[www.marfan.org](http://www.marfan.org) or call (800) 8 – MARFAN.

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Lori Mitchell, illustrator of this book, graduated with honors from the Art Center College of Design with a BA in Illustration. She has illustrated nine books to date. Her most famous is titled *Different Just Like Me*, which she both wrote and illustrated. It talks about how we are all so different and at the same time, so much alike. The book was featured on “Oprah” and won many awards. Lori’s dad, who had Marfan syndrome, can be seen in the scene at the train station in *Different Just Like Me* [www.differentjustlikeme.com](http://www.differentjustlikeme.com). You can’t miss him — he’s the tallest one there. Her daughter April is the main character.

Lori lives in San Diego and teaches elementary school, college and private school art classes.

The characters in this story are real doctors and families dealing with Marfan syndrome. Lori met many of them at the Marfan conference at Stanford University. Lori and April had fun coming up with the hidden pictures in each illustration and hope you will have fun finding them.



The Marfan Foundation is the only nonprofit health organization in the U.S. devoted to saving lives and improving the quality of lives of individuals and families affected by Marfan syndrome and related disorders. Its mission includes research, support, education and advocacy.