

SOFIA

LEARNS ABOUT RESEARCH



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Alexandra Marrone,
and Teresa Quattrin, MD

Illustrated by
Isabella Bannerman

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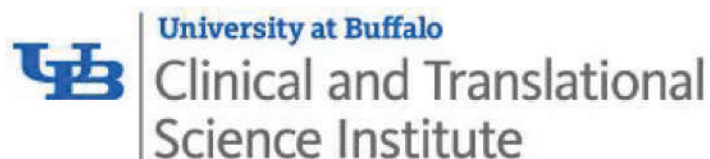
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Sofia was bored. She and her brother, Michael, were at the doctor's office, again. Sofia had **asthma** (said like az-muh). This is a condition that can make it hard to breathe. Sometimes Sofia would wheeze, cough, and her chest would feel tight. **Wheezing** means there is a whistling sound when she would breathe. She had to go for **check-ups** a lot to make sure she had the right **medicine** to help her lungs work. She was tired of going to the doctor's.



Dr. Wilson came in. He said, “Do you want to do something special to help other kids with **asthma**?”

Sofia thought, “*This is new. I wonder what this means? It sounds good.*” She was a little too nervous to say anything.



Then she looked at her dad. Her dad said, “Maybe. Can you tell us a little more?”

Dr. Wilson said, “I would like you to meet someone who can tell you more about it. Dr. Amanda Quinby is a **scientist**. You can call her Dr. Q. She can tell you all about a **research study** that you might want to help with. It will help us understand **asthma** better. What we find will help us help other children with **asthma**.”

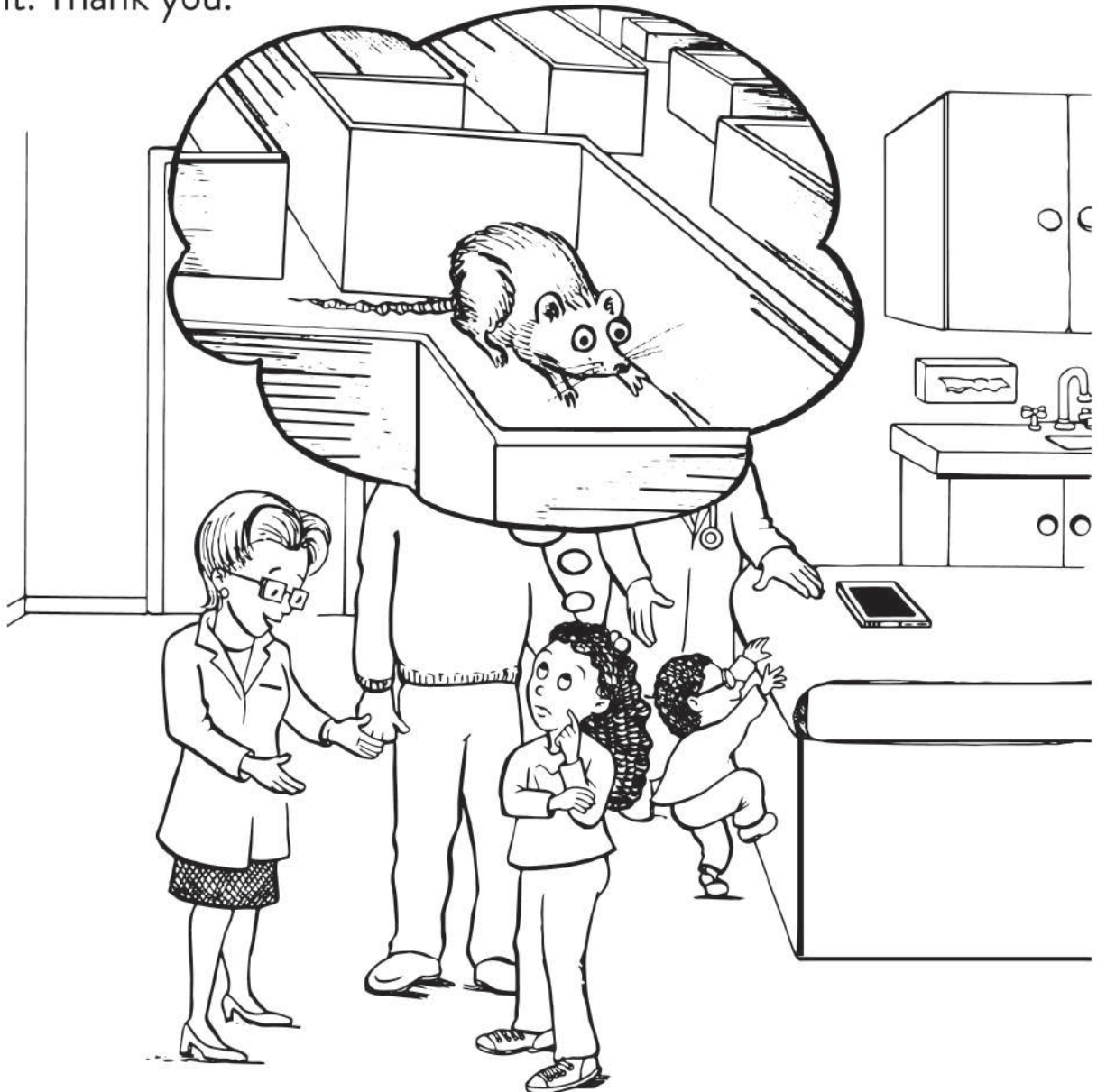
Sofia heard the words “**scientist**” and “**research**” and got a little scared. She thought about movies with mad **scientists** and wild **experiments**. She was not a guinea pig!



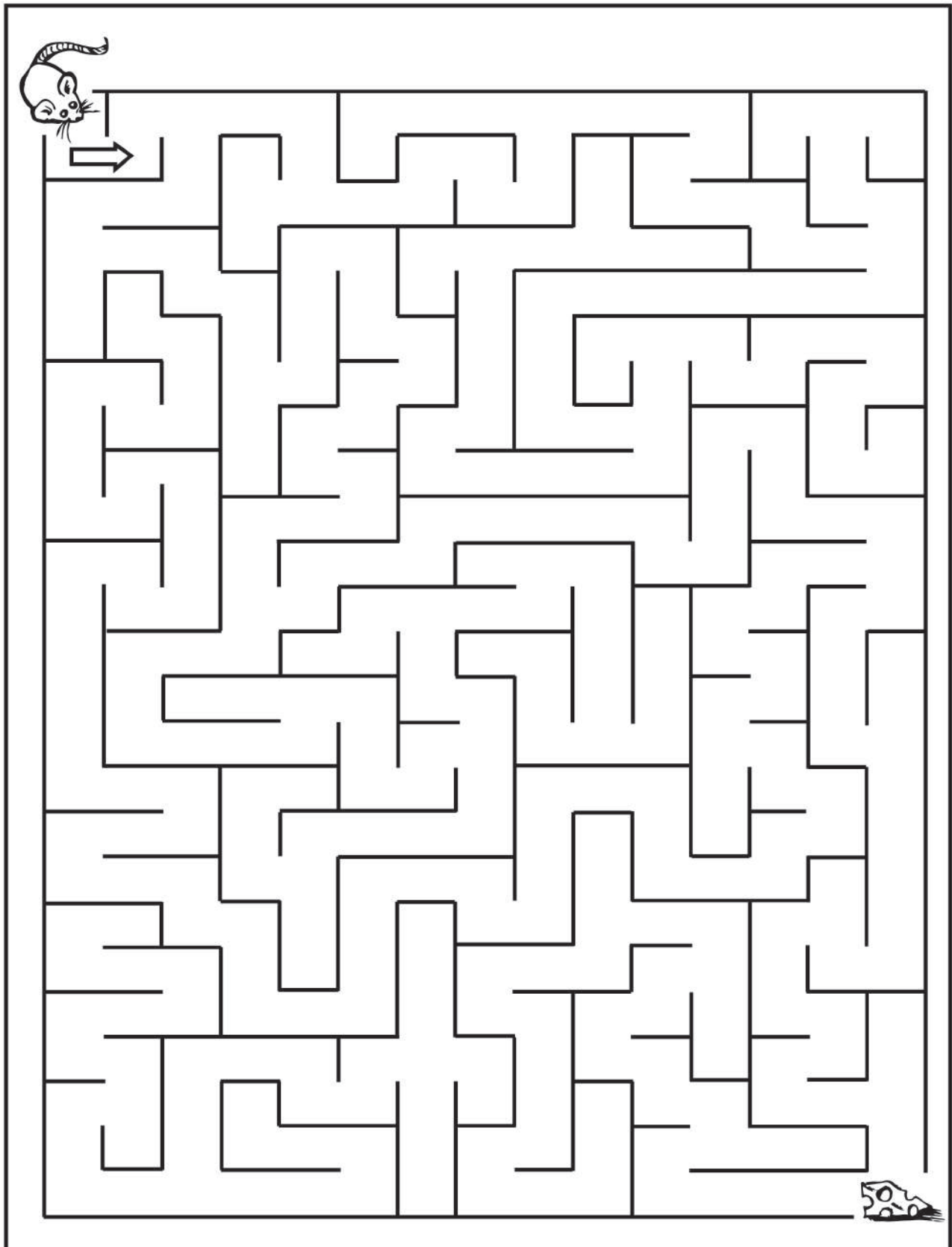
Dr. Q. walked in. Sofia felt a little better when she saw that Dr. Q didn't look scary at all. She was smiling and had glasses just like Michael.

"Hi, Sofia! It's nice to meet you. Hi, Mr. Moreno! And who is the little fellow here?" she said, looking at Michael. He was still climbing on the chairs. "I'd like to tell you about my **research study**. Is that okay with you?" said Dr. Q.

Sofia's dad said, "It's nice to meet you, too. We would like to hear more about it. Thank you."



Sofia started to think of research about rats finding their way.
Can you help this rat find the cheese?



Dr. Q saw that Sofia seemed nervous. She said “Do you have questions about **research**? It is a lot more than rats in mazes! **Research** can help us learn how to treat **illnesses**. Sometimes it helps us understand what people think about things in the world around them.

And sometimes **research** helps us make better **medicine**. Kids need different **medicine** than adults. Your bodies are different, and they think differently too! We need to make sure those **medicines** work.”

Sofia liked the idea of helping other kids. But she was still nervous. Her dad looked nervous too. Dr. Q said, “Please. Let’s talk about **research** first. What do you want to know? I am happy to answer any of your questions.”

“So what IS a **research study**?” was the first thing Sofia blurted out.

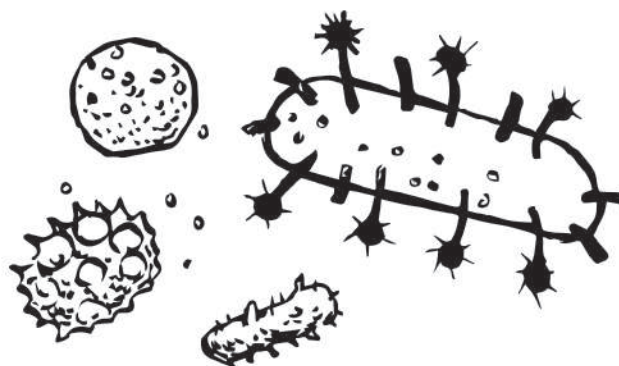


Dr. Q. said “Great question! A study is a lot like a **science experiment** you might have done in school. We start with a question about something. Then we think about how we can find answers to that question. We will sometimes guess at what we think the answer is and our guess is called a **hypothesis**.”

Michael became interested in what Dr. Q was saying. He said, “Can I help do **research** too? I don’t have **asthma**.”

Dr. Q said, “Of course! Anyone can help with **research**. Some studies need help from people with an **illness**. Other studies need help from people without an **illness**. We need everybody’s help to learn how to take better care of people!”

Sofia needed to think about all of this, and she wasn’t sure she could remember...



Can you help Sofia find all the words she just learned about?

Sofia's Words

I P W Y S C I E N T I S T W F
H J K N O W L E D G E W U N E
Y N L K H E L P O R I N A R X
P V Q U E S T I O N T A Y N P
O S T U D Y A G F C F H Y G E
T O H M Q S R L E K O B T R R
H L J A A R C B E U Z H R E I
E L K U M E D I J A V X E S M
S K X I C E I N E W R H A E E
I D Y M E E D S Y N N N T A N
S O Z P G N R I U O C X M R T
L C L R E H W W C R N E E C P
R T B O T E U Y U I V P N H B
N O E V F J E U E D N E T E B
E R H E L E H Z O R X E Y O S

LEARN
KNOWLEDGE
MEDICINE
RESEARCH
SCIENTIST

TREATMENT
HELP
QUESTION
HYPOTHESIS
STUDY

SURVEY
IMPROVE
SCIENCE
EXPERIMENT
DOCTOR

Sofia's dad had some questions for Dr. Q too. "Are there different kinds of **research**?" he asked.

"Yep! There are many types of **research**!" Dr. Q said, "Sometimes we ask people to take a **survey**. This means you answer questions on a piece of paper or a computer about yourself.

Other times we ask people to try doing something new or different to see if it makes them feel better. This may mean taking a different **medicine** or eating different foods, or many other types of things.



Scientists or **researchers** may watch people and take notes. This is called **observation**. They also might read what people write on a **survey**. This helps them learn about the people in their study. **Scientists** might ask you to take some notes about what you are doing each week that you are in a study. All of this information is called **data**."

You might be asked to participate in a **focus group**. That is when a group of people come together to talk about a topic that the **scientist** is interested in learning more about.



You might be asked to complete a **survey**. This is where you answer questions on paper or on a computer about yourself.

Practice taking a **survey**! Write your answers to the questions.

1. How old are you? _____

2. In what city do you live? _____

3. What are your favorite foods? _____

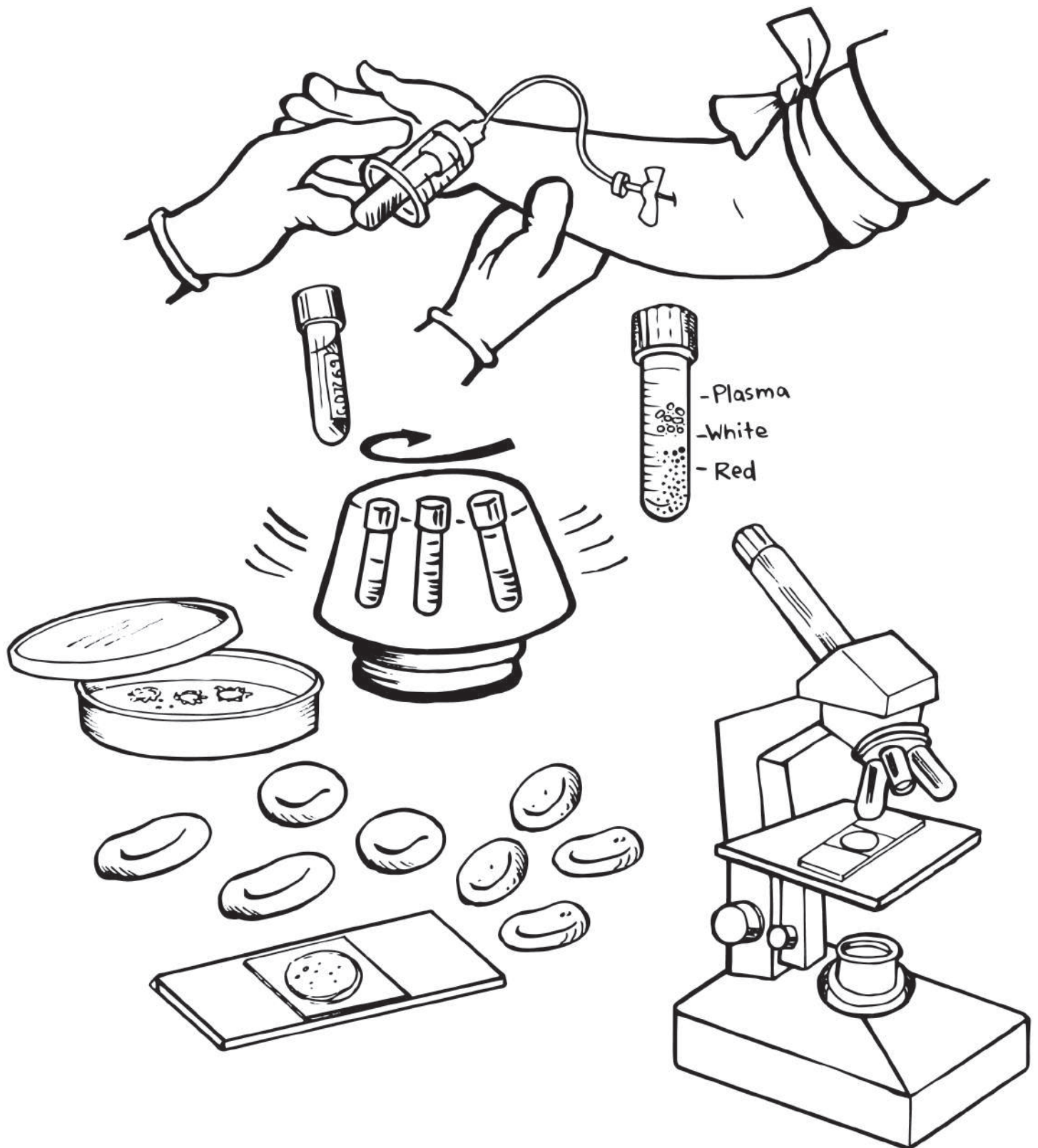
4. What do you like to do for fun that is also exercise? _____

5. Do you have any pets? (circle your answer)

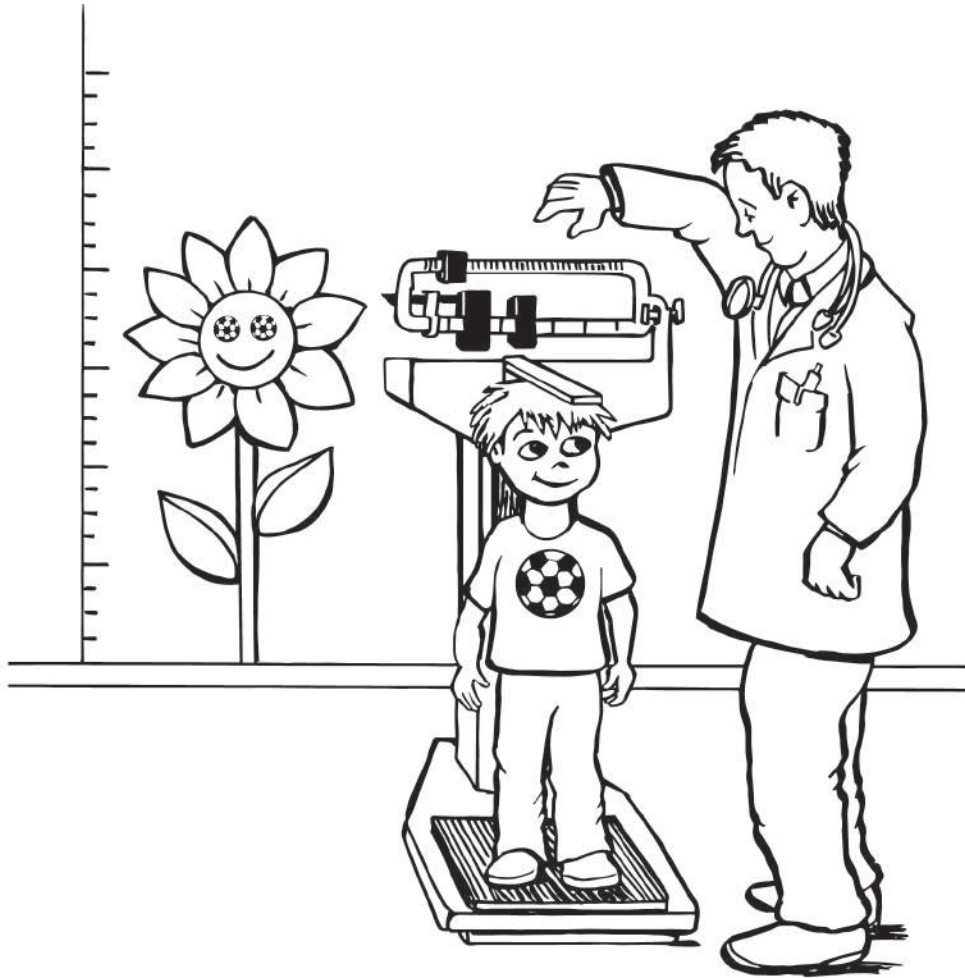
Yes No

6. If yes, what kinds of animals do you have?

Sometimes scientists ask you to give a sample of blood to understand what's going on inside your body.



Some **scientists** will ask if they can measure how tall you are, how much you weigh, or even how big around your head is! This helps them learn more about how your body is growing.



Sofia is learning about the different **data** that **scientists** collect. Can you share some **data** about yourself?

Do you know how tall you are? _____ feet _____ inches

Do you know how much you weigh? _____ pounds

What size shoe are you? _____

Sofia saw the word **clinical trials** on the sign on the wall. “What does that mean?” asked Sofia next.

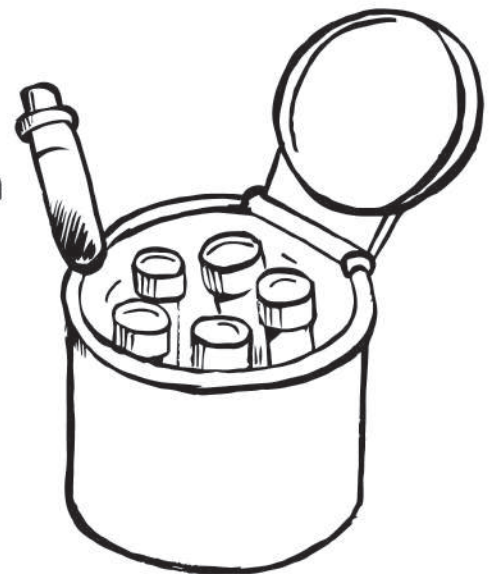
“Another great question, Sofia. A **clinical trial** is when you try out a new kind of **treatment**, like a **medicine**, to see if it works.

Sometimes the people in the study actually try the new **medicine**. Sometimes the people in the study take a pretend **medicine**. This is called a **placebo**.”

Sofia thinks this is a little strange. “Why would they take a pretend **medicine**?” she asked.

Dr. Q said, “That does seem funny, doesn’t it? Well, if the people in the study start to feel better, the **scientist** wants to make sure it is because of the **medicine** and not because of something else that happened in the **study**.”

Dr. Q explained a little more. “There is also a kind of **study** where some people try a new **medicine** and other people try an old one. This is to see if the new one works better.”



Sofia was thinking, 'This kind of makes sense. I remember when I used to tie my shoes one way and they always came untied. That was really annoying. Then my mom showed me a different way to do it.'



'When I tie my shoes the new way, they stay tied all day. Now I don't trip on them anymore. It's great!'

Scientists often try to figure out how two different **medicines** are different. This takes good **observation** skills.

Can you help Sofia find the difference between these two pictures?

The first one is how she looked after taking a hike on a hot, sunny day without bug spray and sun protection. The second picture is how she looked the following week after remembering her bug spray and sun protection.



There are 12 differences. Did you find them all?



Differences on the playground: 1. No flying bugs 2. Long sleeves and pants on Sofia 3. No bug bites on Sofia 4. Long sleeves and pants on Michael 5. No bug bites on Michael 6. Hat on Sofia 7. Bottle of bug spray 8. Kid playing with ball instead of truck 9. No kid on slide 10. Flower near Michael 11. Butterfly 12. Bird on Sofia's bench

Michael was getting a little confused, “That’s a lot of stuff to keep track of!”

Dr. Q said, “It sure is a lot of **data**! But it is actually kind of fun! And all of these different kinds of studies have two things in common. First, they all help us learn more about being healthy.”



“Second, and most important, you can only be in a study if you **AND** your parents give your **consent**.”

Sofia heard a word she was not sure of. She asked “Wait. What **IS consent**?”

“**Consent** is when you agree to be in the study,” answered Dr. Q.

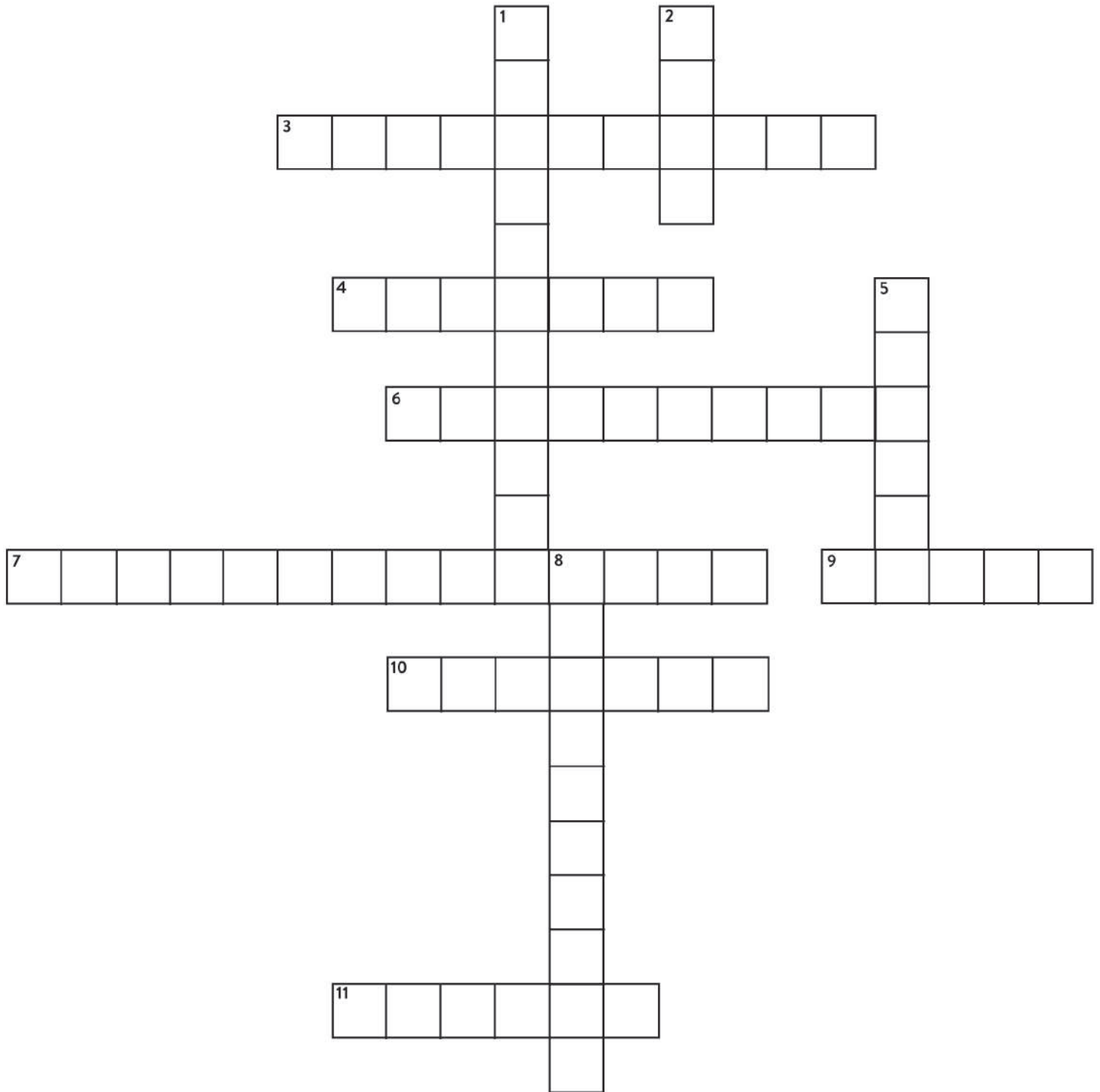
“It’s when you say that you want to be in a study after you learn about what the study is. It’s my job to tell you exactly what you would do if you were in the study. I have to tell you the good things that can happen and also the bad things. Then, you would decide if you wanted to do it.”

“Since you’re still young, we also talk with your parents about a study. They can help decide with you if it’s a good idea. If you all think it is, then they give **consent** for you to participate. You would also have to **assent** to the study. This means that you agree that you want to do it. If you agree to be a part of the study and give **consent** then you’ll be called a **participant** which is what a person who is in a study is called.”



Lots and Lots of Research Words

Complete the crossword below



Across

3. Watching and taking notes about how a treatment is working in a person
4. A pretend medicine with nothing in it that is used to help find out if a new medicine works
6. A guess about how something might work or how two things may be related to each other
7. A study where researchers compare different treatments or medicines to figure out which ones work best (2 words with a space in between)
9. Like a science experiment, it's what scientists and researchers do to try to answer a question
10. A person's agreement to be part of a study
11. A paper or online set of questions that you answer to help with a study

Down

1. A person that is in a study
2. The information collected in a study. This can be numbers like age and height or words, like about how you feel.
5. A child's or teenager's agreement to be part of a study
8. A person that is gathering information in the study

Crack the Code!

Help Sofia figure out the hidden message!

13 2 19 2 7 13 18 5 13 7 8 12 2 13 19

5 2 1 11 19 15 1 21 2

11 13 15 14 1 2 6 19 !

A	B	C	D	E	F	G	H	I	J
7	14	18	3	2	22	12	5	24	17

K	L	M	N	O	P	Q	R	S	T
25	1	6	8	15	11	10	13	19	9

U	V	W	X	Y	Z
4	21	16	26	20	23

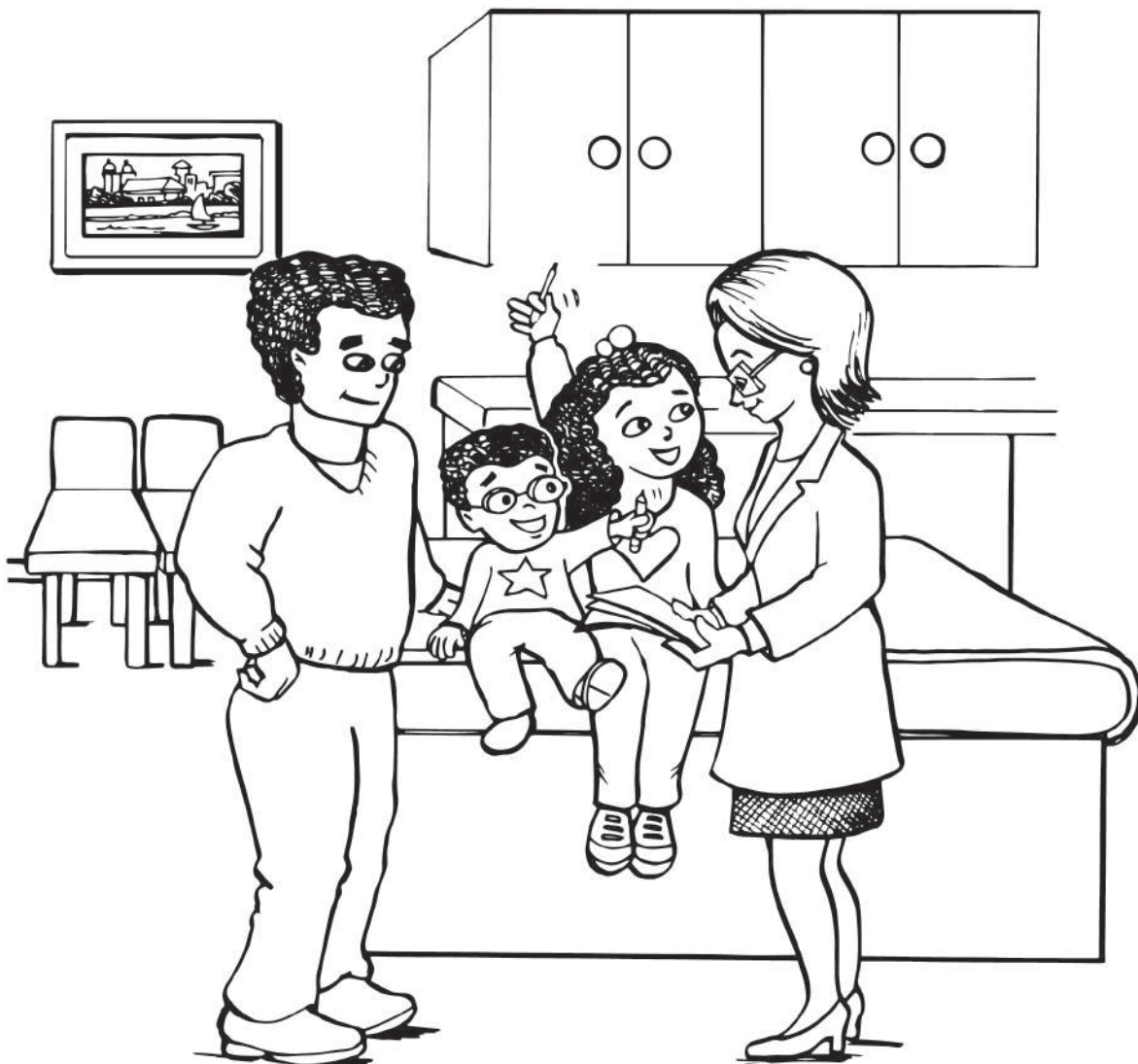
SOLUTION: Research Rangers Help Solve Problems!

Sofia was pretty sure she understood. She said, “Okay, we have to tell you that it’s okay for us to be in the study and you’ll tell us if there are any bad things that could happen?”

“Absolutely,” said Dr. Q, “Can I tell you about my **research study**?”

Sofia and Michael were excited, and said at the same time “Yes!”

Dr. Q explained, “In my study, you will come into the doctor’s office a little more than you usually do. We will sometimes do **check-ups** to make sure you are feeling okay. Sometimes, we might take a blood **sample** from you with a needle. Blood helps us learn about what’s going on inside of you, so we know you’re healthy inside and out! There are other tests that will help us with that too.”



Sofia didn't like needles, but she did like being healthy. Dr. Q seemed like someone she could trust. She answered her questions and was very friendly.

Then Sofia started to worry about how often "sometimes" was. She liked to hang out with her friends and didn't want to miss anything because of **research!** She frowned a little bit. She also was worried about how she would explain it to her friends.



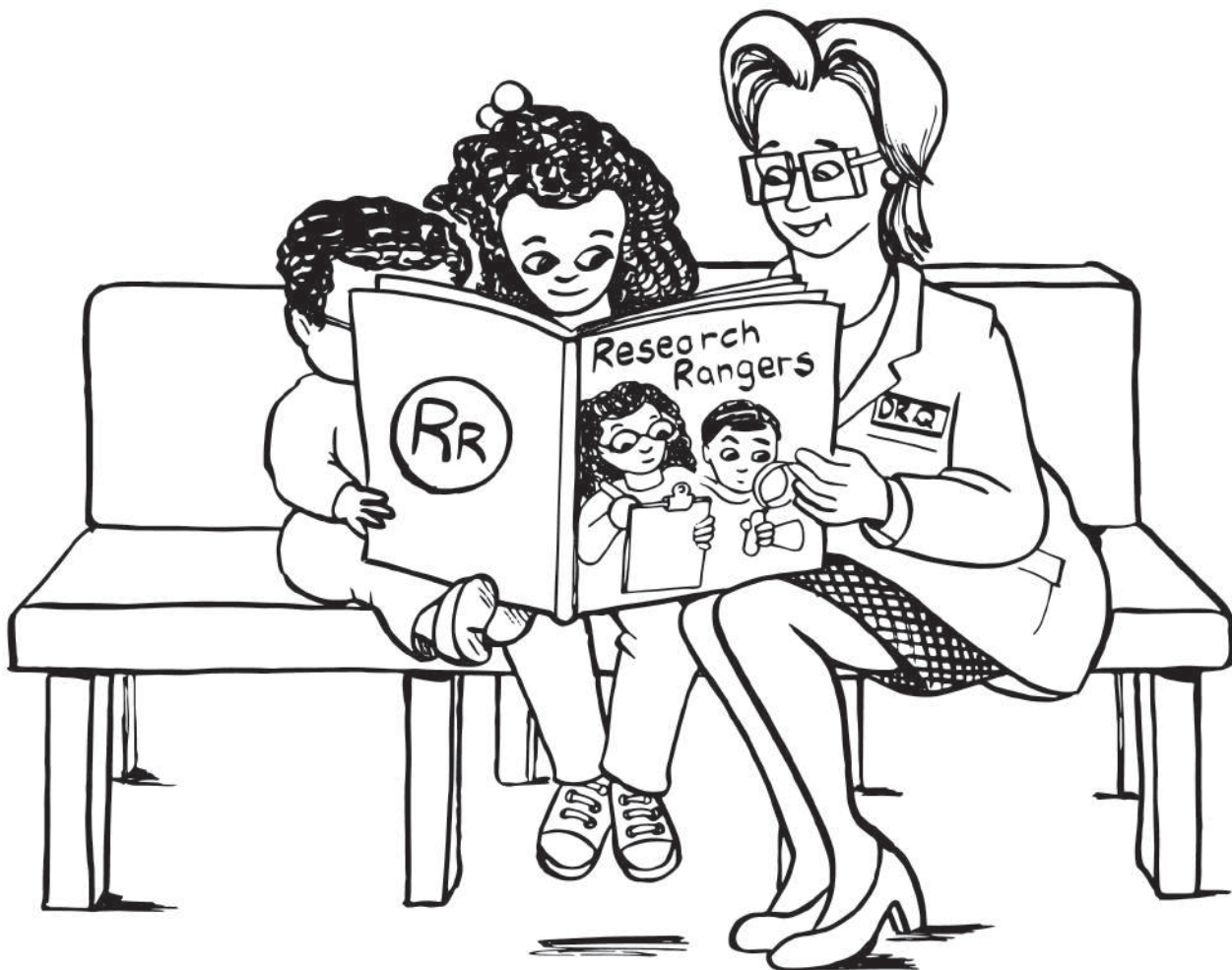
Dr. Q noticed Sofia's sad face. She asked "Sofia, are you a little worried about being too busy?"

Sofia nodded, "Yes. And I'm also worried about how to tell my friends about this when they ask about it."

Dr. Q said “Don’t worry Sofia. We want to make sure the study works for you. Please tell us if the study has too many visits to the doctor’s office. Tell us if the visits are at bad times for you. We will work with you to see what is best for you!”

Dr. Q also said, “We can give you copies of a book we made to help your friends understand what you’re helping us with. It’s about a sister and brother who help with **research** studies. They become the **Research Rangers** who help solve problems and improve kids’ health all over the world!”

Sofia was feeling a lot better. Sofia’s dad did too. He said, “Your mom is going to want to hear all about this too, Sofia! Maybe we can bring the book home today and you can tell her all about it.”



Sofia had one more question. **It was important!**

“What if I want to stop?” she asked.

“You can stop at any time!” said Dr. Q, “One of the most important parts of **research** is making sure that you are feeling okay about it. If you decide that you do not want to do it anymore, that’s okay. We won’t be mad. You are allowed to stop whenever you want.”

“Phew!” said Sofia, “Wow! You answered so many questions Dr. Q.”

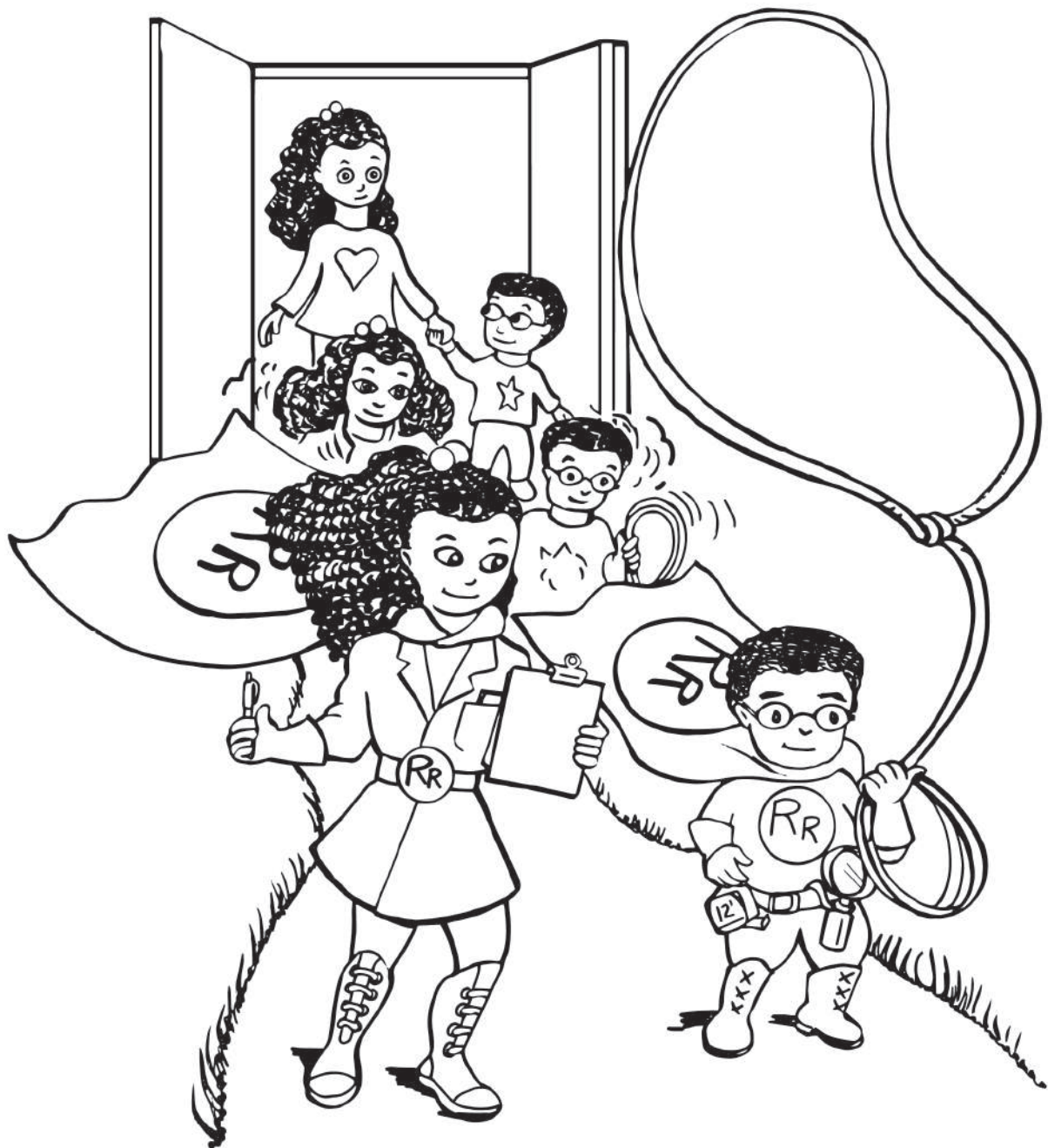


Connect The Dots!

“Answering questions is my job!” Dr. Q said. “My job is to connect all of the dots to make sure you see the whole picture. If you decide to help with a study, my job is to make sure that you are feeling okay while you’re helping. It’s up to you to decide if you want to help us. You have a chance to help other kids, and who knows, maybe even change the world!”

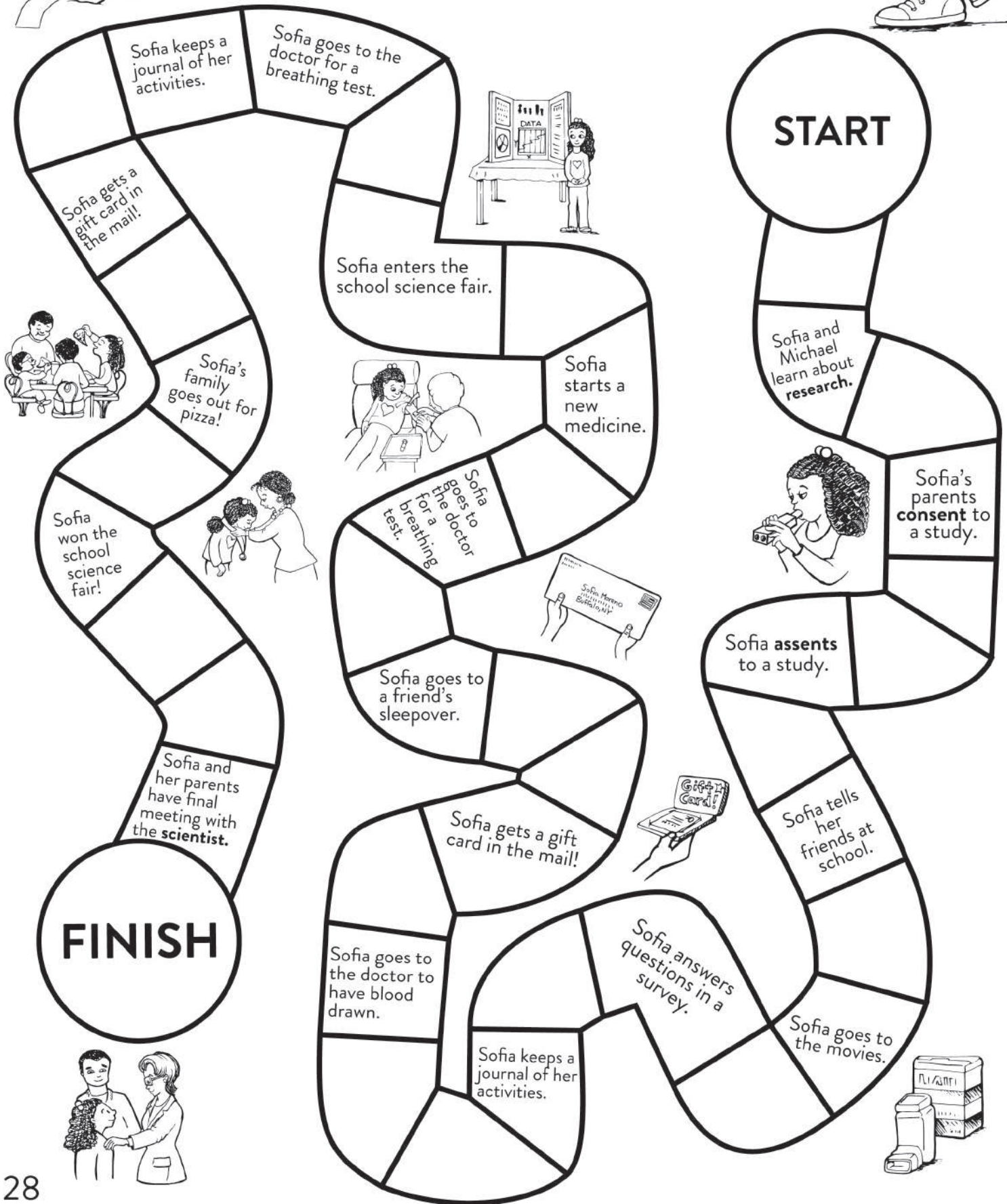
“What do you think? Would you like to participate in my **study**?” Dr. Q asked Sofia and her dad.

Sofia said, “I think I would like to do that! I want to help change the world!”





Walk with Sofia Through the Research Process



Glossary of Words

Assent: A child's or teenager's agreement to be part of a study.

Asthma (said like Az-muh): A disease that some people have that makes it hard for them to breathe sometimes. We use our lungs to breathe. Lungs are in our chest behind our ribs. Inside the lungs are tubes. These tubes carry the air in and out of our lungs. When someone has asthma, the tubes don't carry the air as well. The lungs get tight and make thick, sticky stuff called mucus. Mucus is kind of like snot. This makes it hard for the person to breathe and they feel like coughing.

Check-ups: Regular visits with the doctor to make sure that you are feeling okay and growing well. You might also have check-ups with a scientist if you are part of a research study. They want to see how you are doing and if you want to still be in the study.

Clinical Trial: A study where researchers compare different treatments or medicines to figure out which ones work best. You might need to go see the doctor or scientist a little bit more often than normal for check-ups during this kind of study.

Consent: A person's agreement to be part of a study. If you are a kid or a teenager, your parents will have to sign a consent form for you to be in a study. Someone should explain everything about the study to you before you or your parents sign it.

Data: The information collected in a study. This can be numbers like age and height or words, like about how you feel. It can even be the notes scientists take from observations.

Focus Group: When a small group of people come together to talk about a topic that the scientist is interested in learning about.

Hypothesis: A guess about how something might work or how two things may be related to each other.

Illness: Makes a person feel sick. An illness can be anything from a cold or the flu to something that lasts longer, like asthma.

Medicine: Something your parent or a doctor might give you to make you feel better when you're sick. There are different types of medicine, they can come in pills, liquids, creams, or even sprays so that they can be breathed in to your lungs. Sometimes medicines help fight off germs that make you sick. Other times they help get rid of pain like a headache or sore throat. Some medicines even replace an important chemical that may be missing in your body. Kids need different medicines than adults.

Microscope: This is a tool that people use to allow them to see very small things. It can help you see things that you can not see with just your eyes. You look into the instrument through a lens (kind of like a magnifying glass). The object you are trying to see may have a light on under it to help you see it. You can see things like very small bugs. You can also look at samples of blood or skin to see how healthy they are.

Observation: Watching and taking notes about how a treatment or intervention is working in a person. Scientists can learn a lot from observing. They can see how something works from month to month. They can see how someone is feeling before a treatment and after a treatment.

Participant: A person that agrees to be in a study.

Placebo: A pretend medicine with nothing in it that is used to help find out if a new medicine works. Doctors and scientists use it to make sure that if a patient starts to feel better it is because of the medicine and not because of something else.

Research: The way a scientist finds out the answers to questions. Research can be observing, experimenting, or even just reading about what other people have done. It helps us find better ways to do things like treat illnesses.

Research Study: A lot like a science experiment. We start with a question that we want to answer, like what happens when we combine vinegar and baking soda. Then we carefully try it out. We watch and listen to what happens and we write it down. Then we have an answer to our question!

Sample: A sample can mean a small amount of something. It can also mean a group of people chosen from a larger group of people to be part of a study. A researcher may say they want to take a sample of your blood. This means they would take a very small amount out with a needle in order to study it under a microscope.

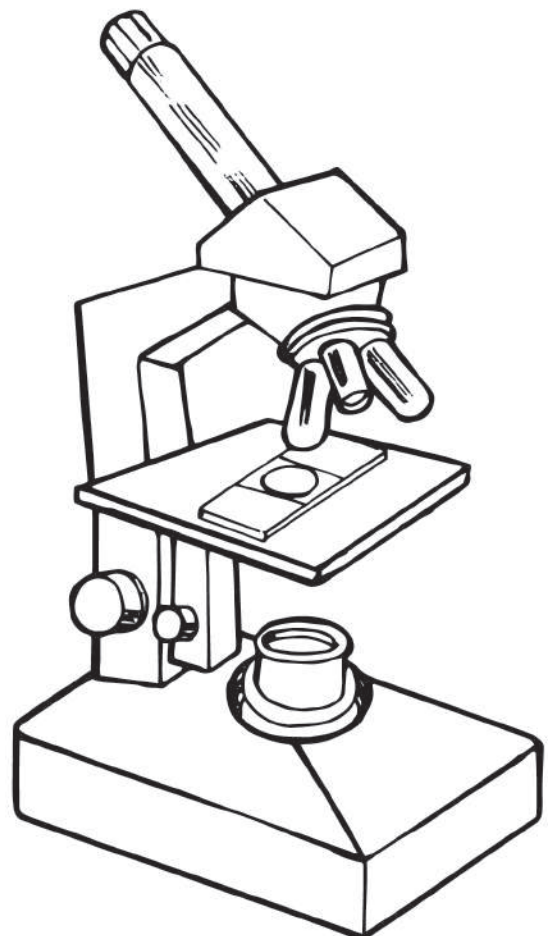
Science Experiment: Anything that you do to help you answer a question. This may involve using your eyes, your ears, your nose, and your sense of touch to learn about something. It involves careful planning. It also involves writing everything down. This helps the scientists remember everything that happens.

Scientist or Researcher: A person who tries to find answers to questions and solve problems. They do this through observations and experiments.

Survey: A set of questions on paper or on a computer, tablet or phone that you answer to help with a study.

Treatment: Something a doctor might give you or ask you to do in order to make you feel better when you're sick. It can be a certain kind of exercise or a kind of medicine or even a new kind of food.

Wheezing: A whistling noise that the lungs make when it is hard to breathe. This happens because the tubes in the lungs are too narrow. Wheezing can be a symptom of asthma, but it can also be because of other things.



**Special thanks to all of the families who helped
us make this book the best it could be!**

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The Liss Family

The Molnar Family

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