

A Note to Caregivers

As a parent, you know that it's not easy to get your child to sit down for a long, complicated discussion, especially about having a condition like cystinosis.

This activity book has been created to help your child continue to learn about cystinosis in an interactive and engaging way. It's filled with helpful information as well as fun things to do. This book is also a great resource to share with your child's teachers, who can use it to help classmates understand why your child sometimes needs to take rests, have a snack, drink water, or wear sunglasses even on cloudy days.

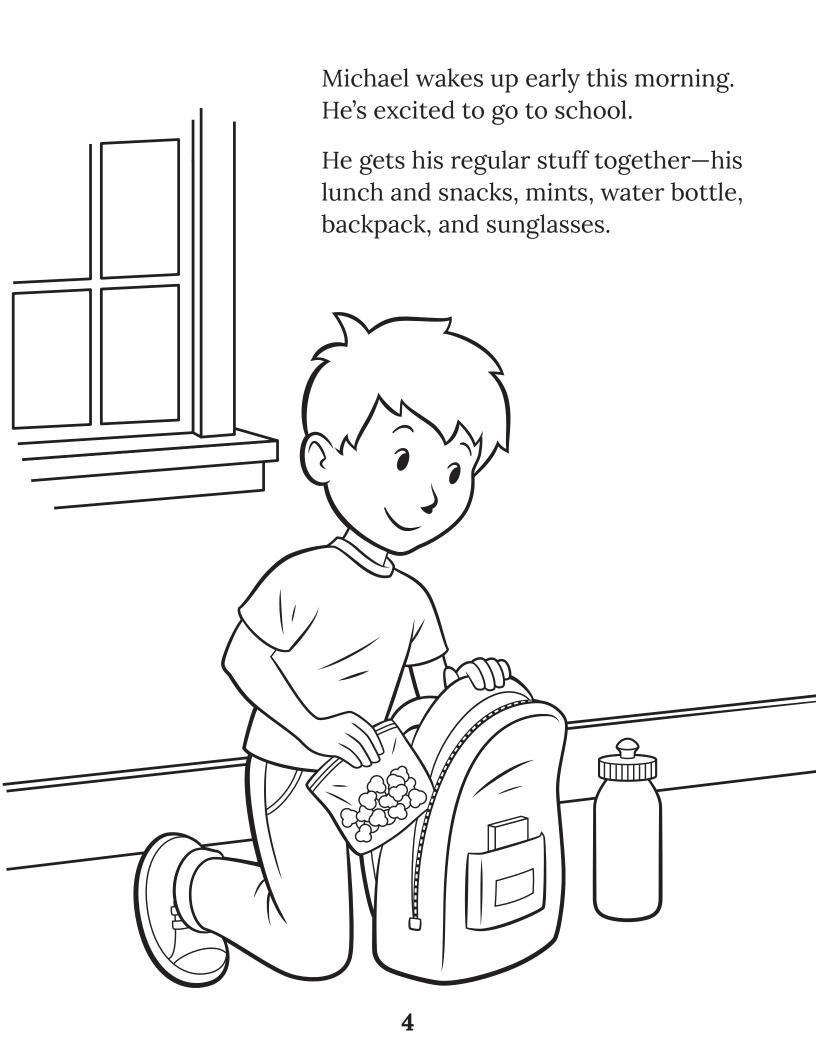
To help you talk with your child about what they are learning from this book, consider asking the following types of questions:

- How are you similar to Michael?
- How are you different from Michael?
- What did you learn from Michael's experience?
- How does cystinosis affect you?
- What do you want your friends to know about cystinosis?
- How can adults at school help you with your cystinosis?

The conversation about cystinosis is one that you, your child, and your family will continue to have for many years to come. This activity book can help keep the discussion going and let your child have some fun along the way.

Michael's Show-and-Tell







Then he and his dad get the box that they packed last night.

The box is for show-and-tell. Today is Michael's turn to share something special he loves. Michael can't wait to show his class what's inside!

What would you bring to show-and-tell?

Draw a picture of something you would love to share with your friends.

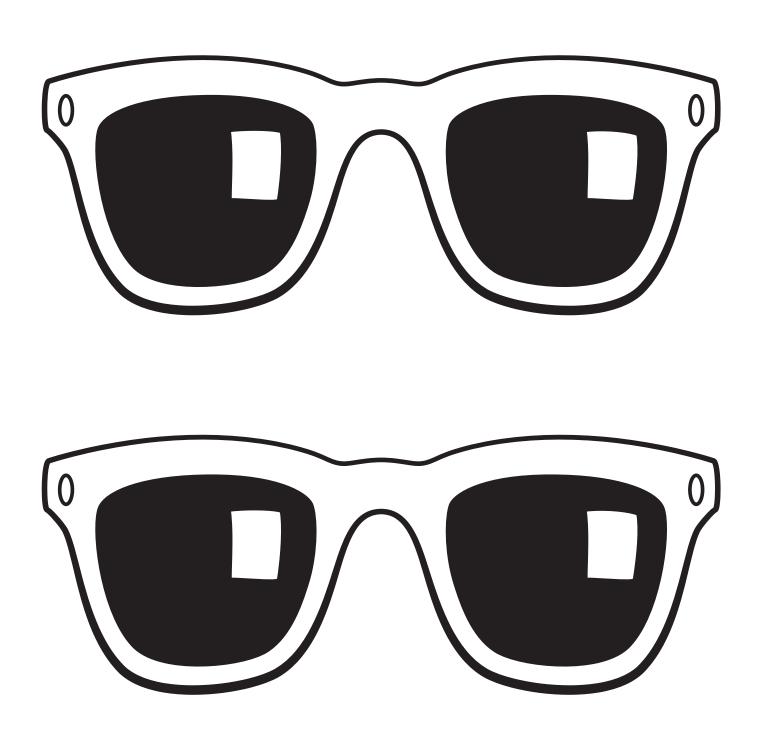
Michael usually rides the bus to school. But his dad drives him in today because his box is too big to go on the bus.

Even though it's a cloudy day, Michael wears his sunglasses. Michael's eyes feel the light more than other kids' eyes do. That's because he has cystinosis. You say it like this: "sis-tin-OH-sis." Cystinosis changes how Michael's body works.



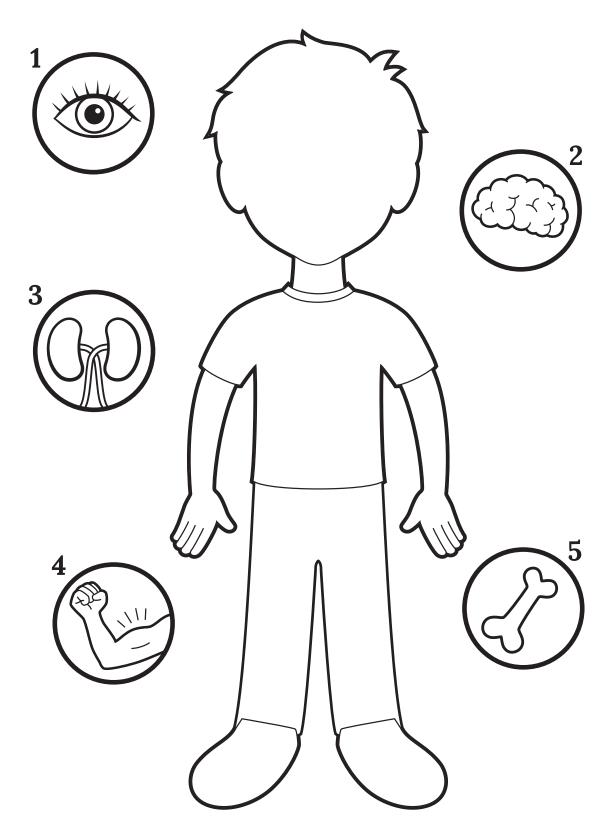
What would your sunglasses look like?

Design a pair of sunglasses for Michael and for you.



What part of the body does what?

Write the number that goes with the matching body part on the next page.



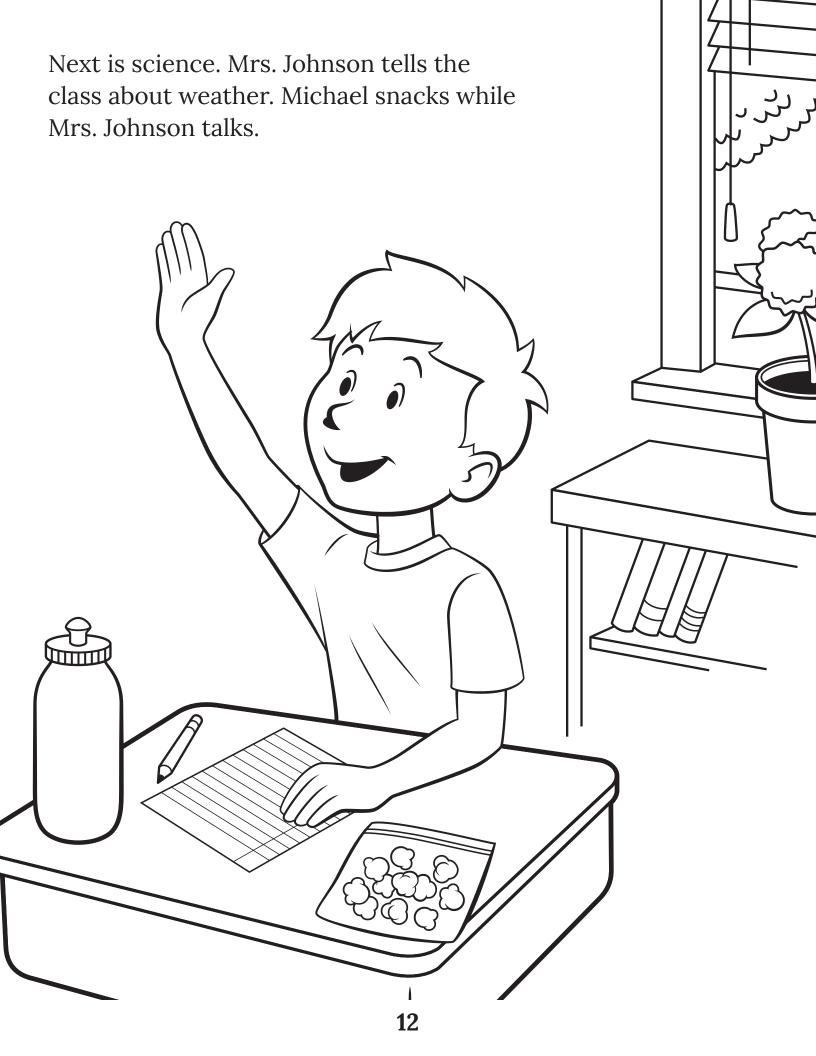
What part of the body does what?

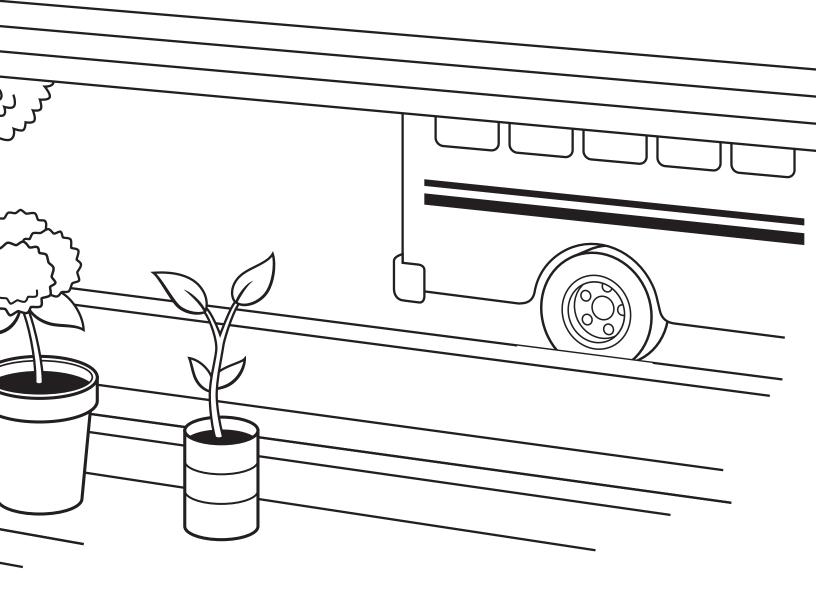
Bones—form your skeleton
Eyes—help you see
Kidneys —help your body get rid of things it doesn't need (hint: they look like beans)
 Muscles—help you move
Brain—helps you think

When Michael gets to school, he wants to open his box right away for show-and-tell. But his teacher, Mrs. Johnson, says the students have other work to do first.

First, there is math. Michael likes numbers.





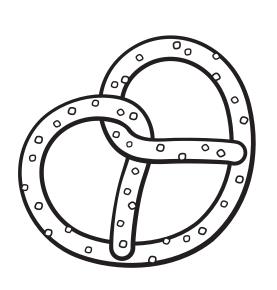


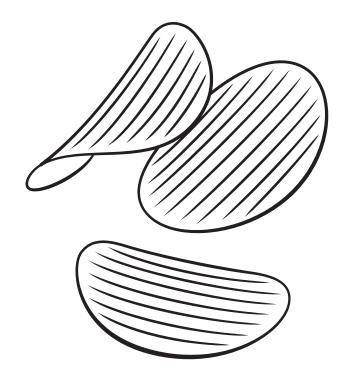
Michael is allowed to have snacks at his desk because it helps him have energy. Sometimes his cystinosis makes him more tired than other kids. He especially likes salty snacks, like pretzels, potato chips, and French fries, which are Michael's favourite!

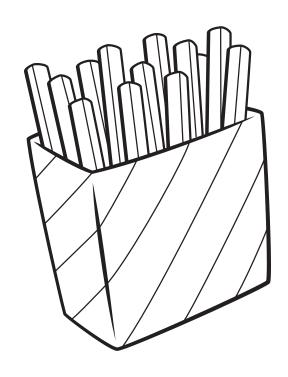
Michael needs water too because cystinosis makes him very thirsty. He uses mints because his medicine sometimes changes the way his breath smells.

Which snacks does Michael like? Which snacks do you like?

Colour them in.









Next, Mrs. Johnson hands out worksheets about the weather. She comes over to Michael's desk.

"Do you want to take a break in the nurse's office now?" she asks. "We're going to do show-and-tell soon. I don't want you to feel tired when it's your turn."

"Yes, please," Michael says. He stops at the boys' bathroom before going to the nurse's office. He goes to the bathroom often because of all the water he drinks. In the nurse's office, there's a bed that Michael can lie down on **NURSE** after he takes his medicine. 15



When Michael gets back to the classroom, Mrs. Johnson says, "It's time for show-and-tell."

Mrs. Johnson calls Emma first. Emma puts her soccer shirt on over her regular shirt. She brings her soccer ball to the front of the class. She tells everyone that she is the goalie on her soccer team.



Jacob's turn is next. Michael feels like he's going to burst! He's having a hard time waiting for his turn!

Michael does his best to wait patiently while Jacob talks. Jacob shows the class his artwork. Jacob draws and paints with very neat lines and bright colours. It is really special!

Finally, Mrs. Johnson calls Michael.

Michael brings his box to the front of the classroom. He opens the box carefully in case something jumps out! He puts his hand in and pulls out all different kinds of dinosaurs. Some are small and some are big. Some have spikes and some have very long necks. These are his favourite toys.

There is a tyrannosaurus rex. Michael calls him
T. rex. There is a stegosaurus, which has spikes on its back. And there is a brachiosaurus, which has a long neck like a giraffe!

Michael tells his friends about the dinosaurs and why he likes them.

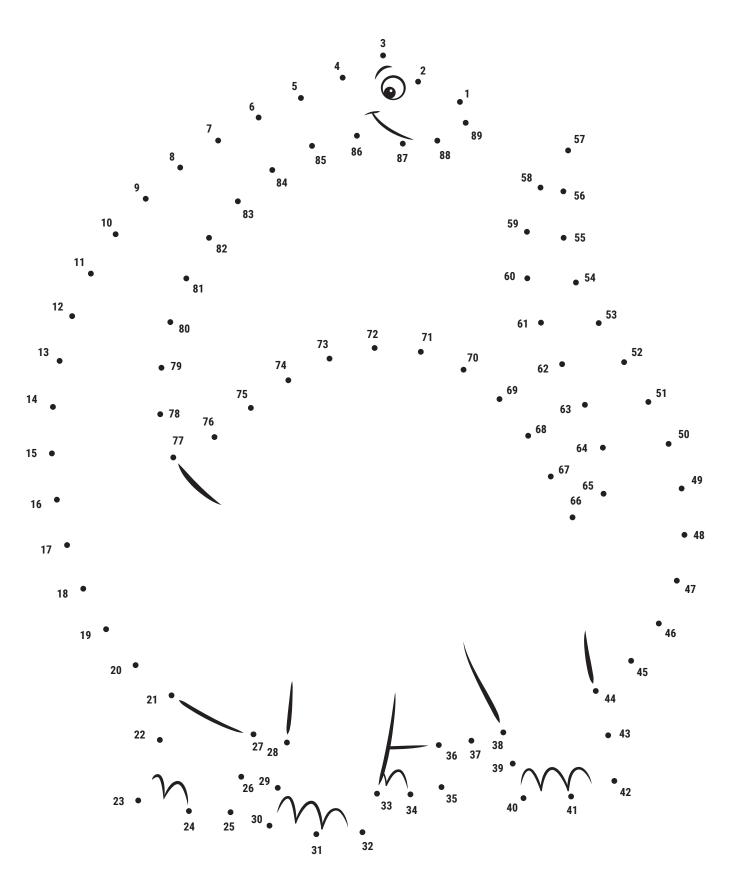
"Those teeth are sharp!" Charlotte says.

"Those spikes are awesome!" William says.



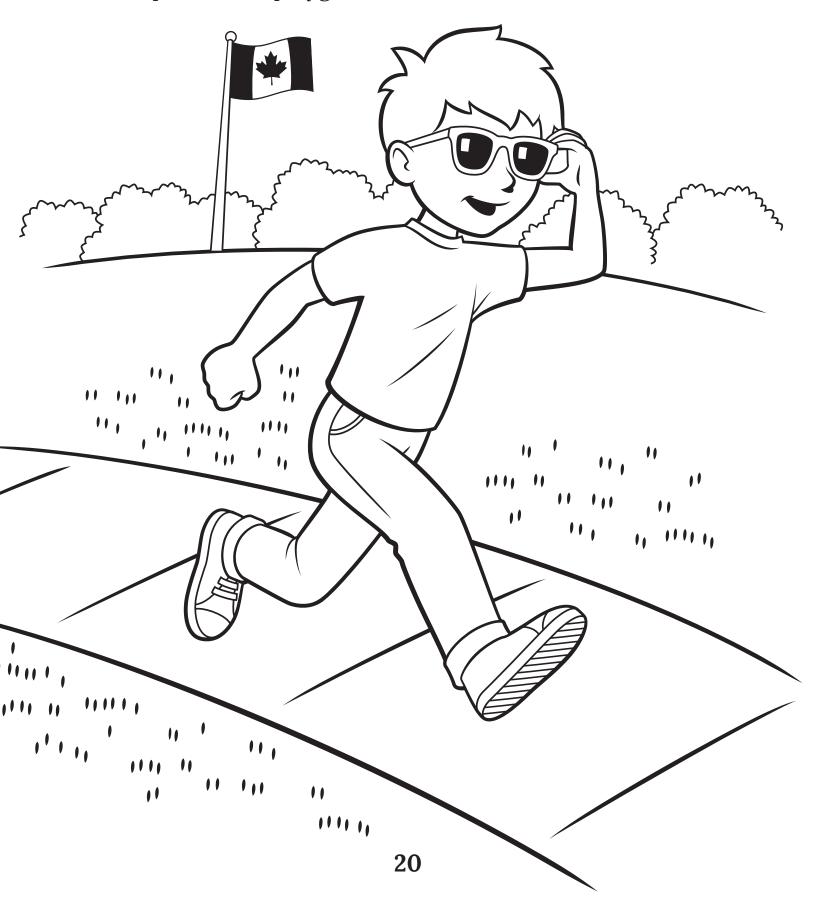
Is this your favourite dinosaur?

Connect the dots to find out which dinosaur it is.

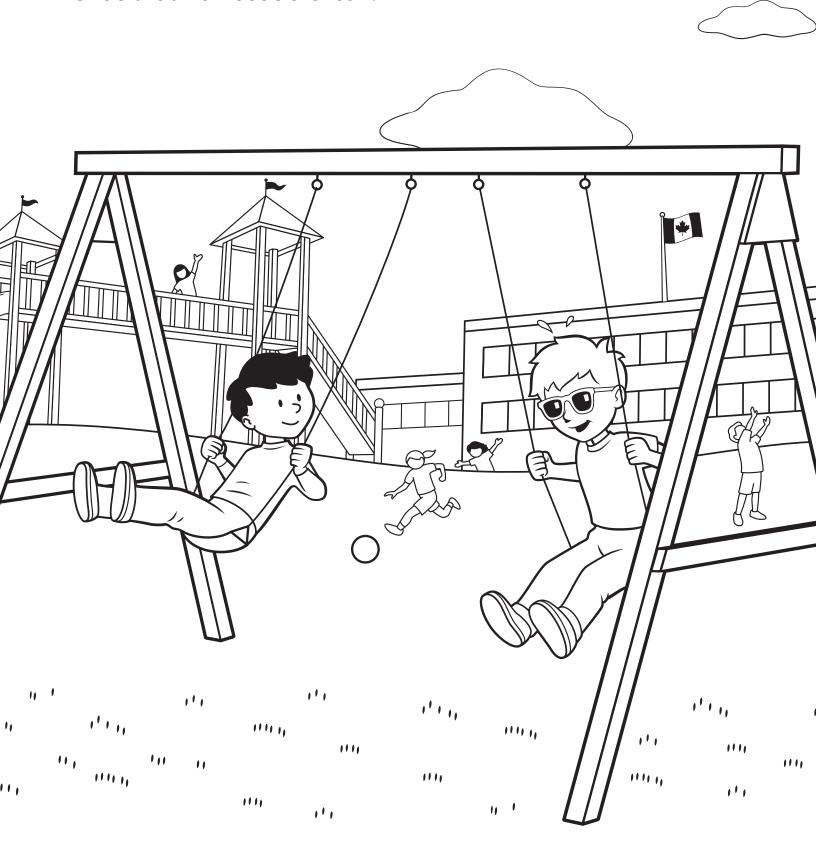


Now it's time for recess! Yay!

Outside, Michael plays with some friends on the swings. That's his favourite part of the playground.



Michael starts to feel a little warm on the swings. Cystinosis makes him feel the heat more than other kids do. So he tells his friends that he needs a break.





They go together to sit under a shady tree. Michael feels happy sitting with his friends. He liked showing his friends his dinosaurs. It was a fun day.



To learn more about cystinosis, visit CystinosisUnited.ca.



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