Annie Has Alport Syndrome

A coloring book created by Alport Syndrome Foundation

ALPORT SYNDROME FOUNDATION

Hello,

We hope you enjoy learning about the characters in *Annie Has Alport Syndrome*, and adding color to their story.

We created this coloring book to encourage conversations about living with Alport syndrome among children and their families, and their doctors. The people involved in creating these characters and this story have Alport syndrome too.

Even though our kidney disease is rare, there are thousands of people from countries all over the world who also have Alport syndrome. Many of them experience some of the same feelings, concerns and hopes.

We have a website with information and videos for people of all ages living with Alport syndrome.

You can find us at www.alportsyndrome.org.

Wishing you all the best,
The Board of Directors and Staff of Alport Syndrome Foundation
info@alportsyndrome.org

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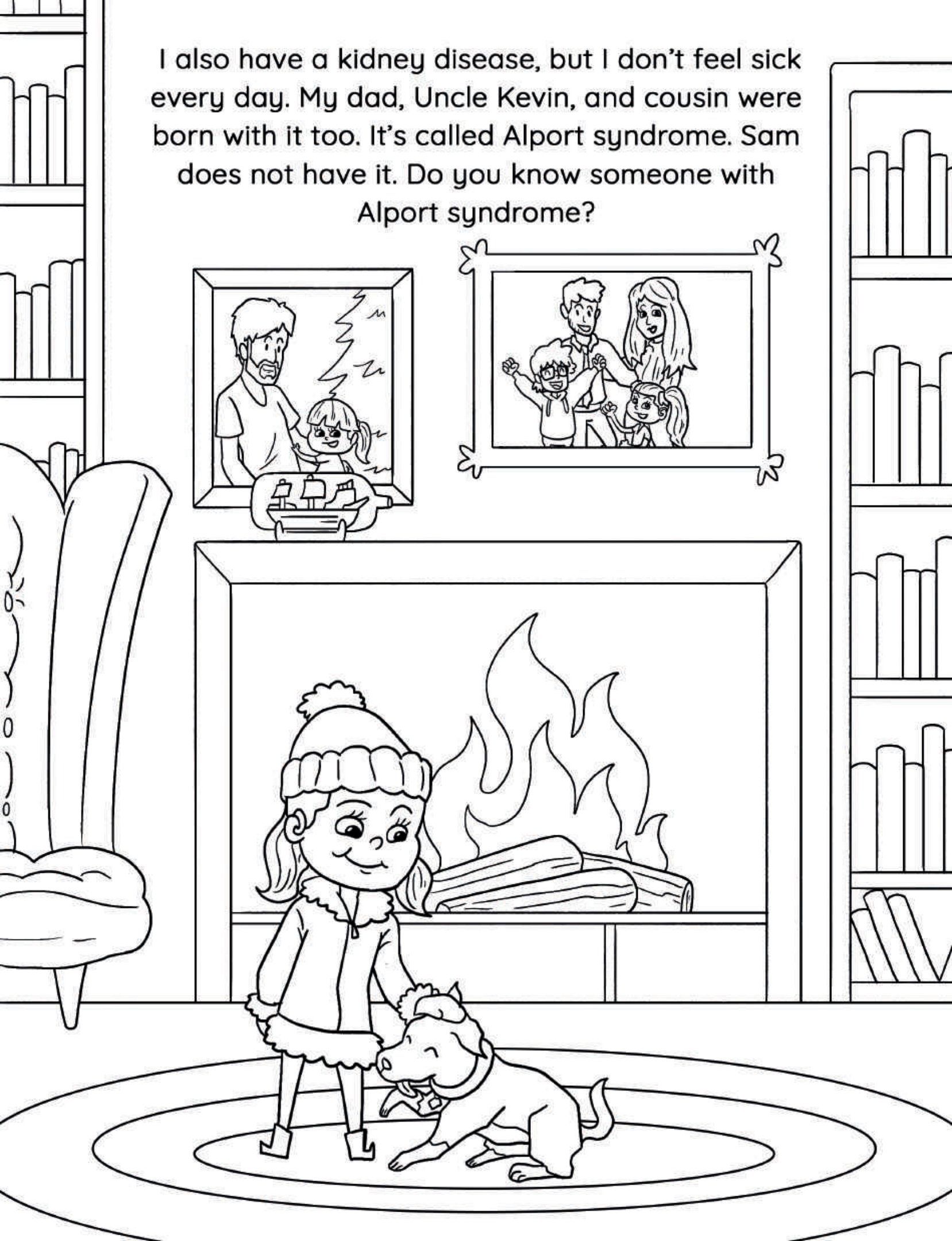
Hello! I'm Annie. This is my big brother, Sam. He makes me laugh.

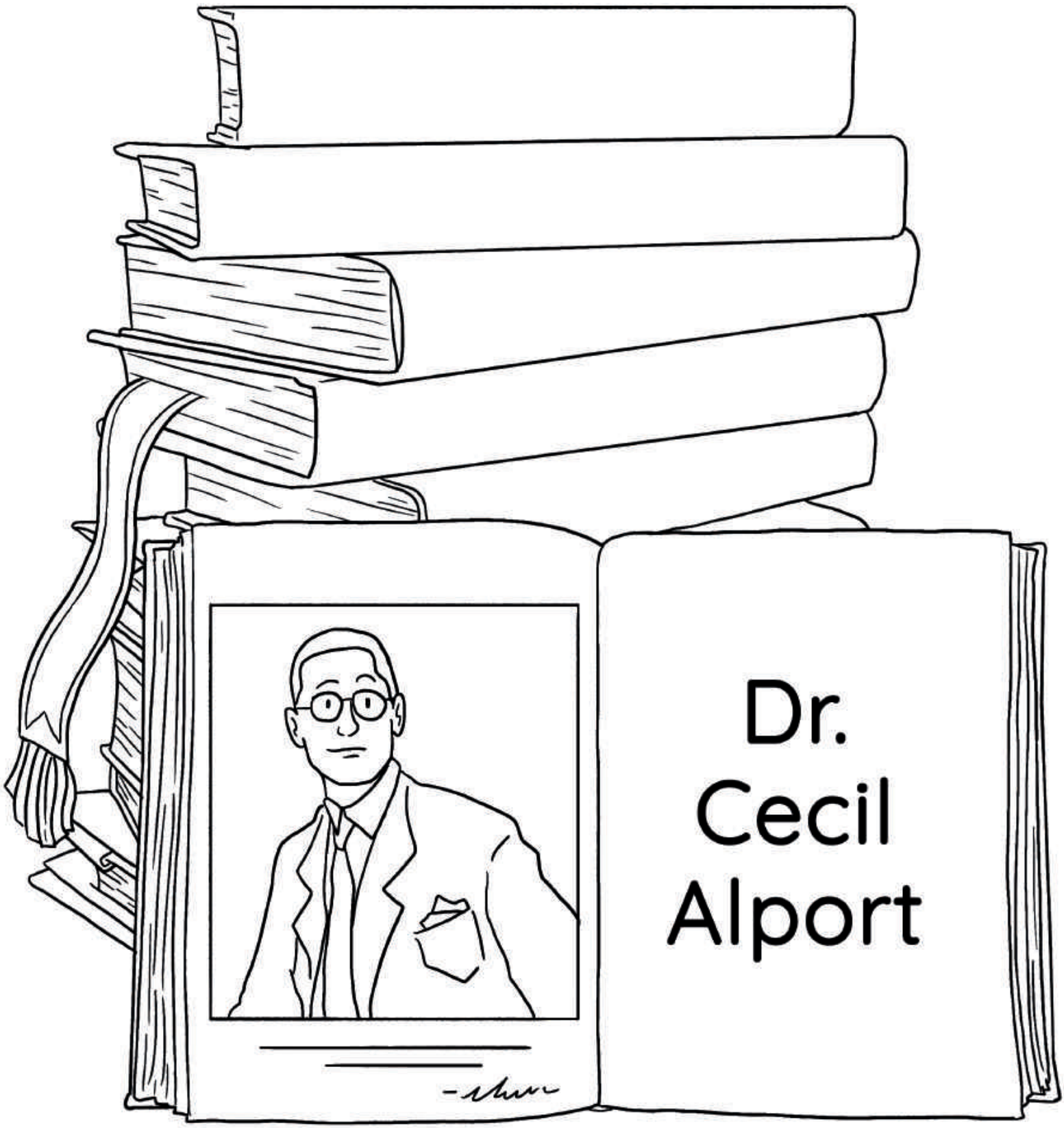
I love dancing, roller skating, and playing with my dog. What are your favorite things to do?

I also have a kidney disease, but I don't feel sick every day. My dad, Uncle Kevin, and cousin were born with it too. It's called Alport syndrome. Sam does not have it. Do you know someone with Alport syndrome?



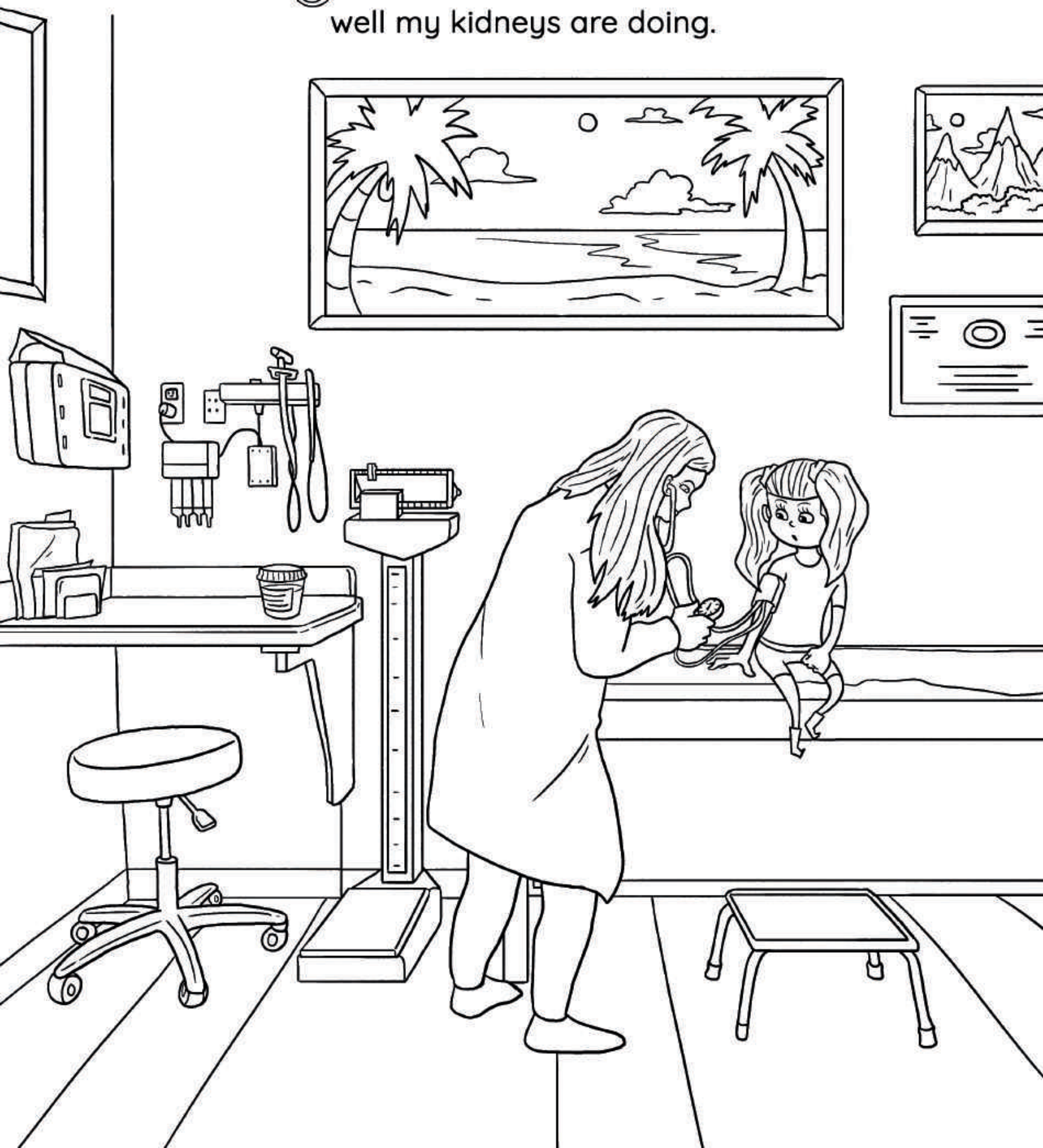
When my Uncle Kevin's kidneys stopped working, his friend gave him one of his own kidneys and it worked. Humans only need one healthy kidney and most people have two. Transplant science and friends can be super amazing.

Almost 100 years ago, Dr. Alport studied a family with kidney problems and hearing loss. It's a good thing he noticed that pattern. Then doctors started looking for medicines for families like ours.

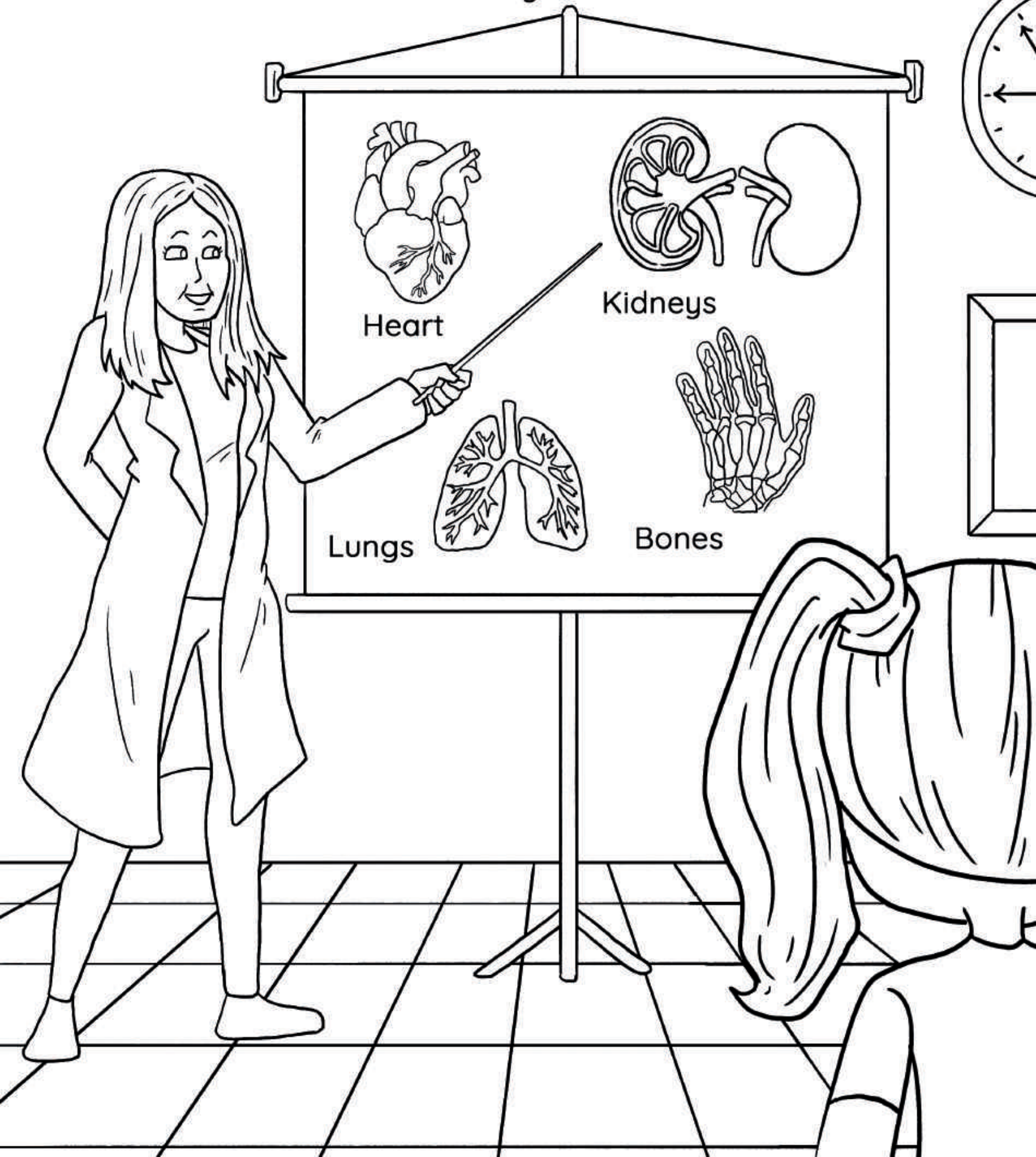


Alport syndrome sometimes causes hearing loss. I didn't know I was missing out on hearing some sounds. I wear hearing aids now. It wasn't easy at first. Now, they are like a part of my body. I hear my family, friends, dog, teacher, birds, rain, music – everything!

Even if I don't feel or look sick, sometimes I leave school early to go for a check-up with Doctor Carter. She is a nephrologist and knows a lot about kidneys. Sam says my pee in the cup looks like apple juice! 😂 All these tests are important to find out how well my kidneys are doing.



Dr. Carter says kidneys have important jobs like cleaning stuff out we don't need, and helping to support strong bones. Kidneys work with other important parts of our body like our heart and lungs.

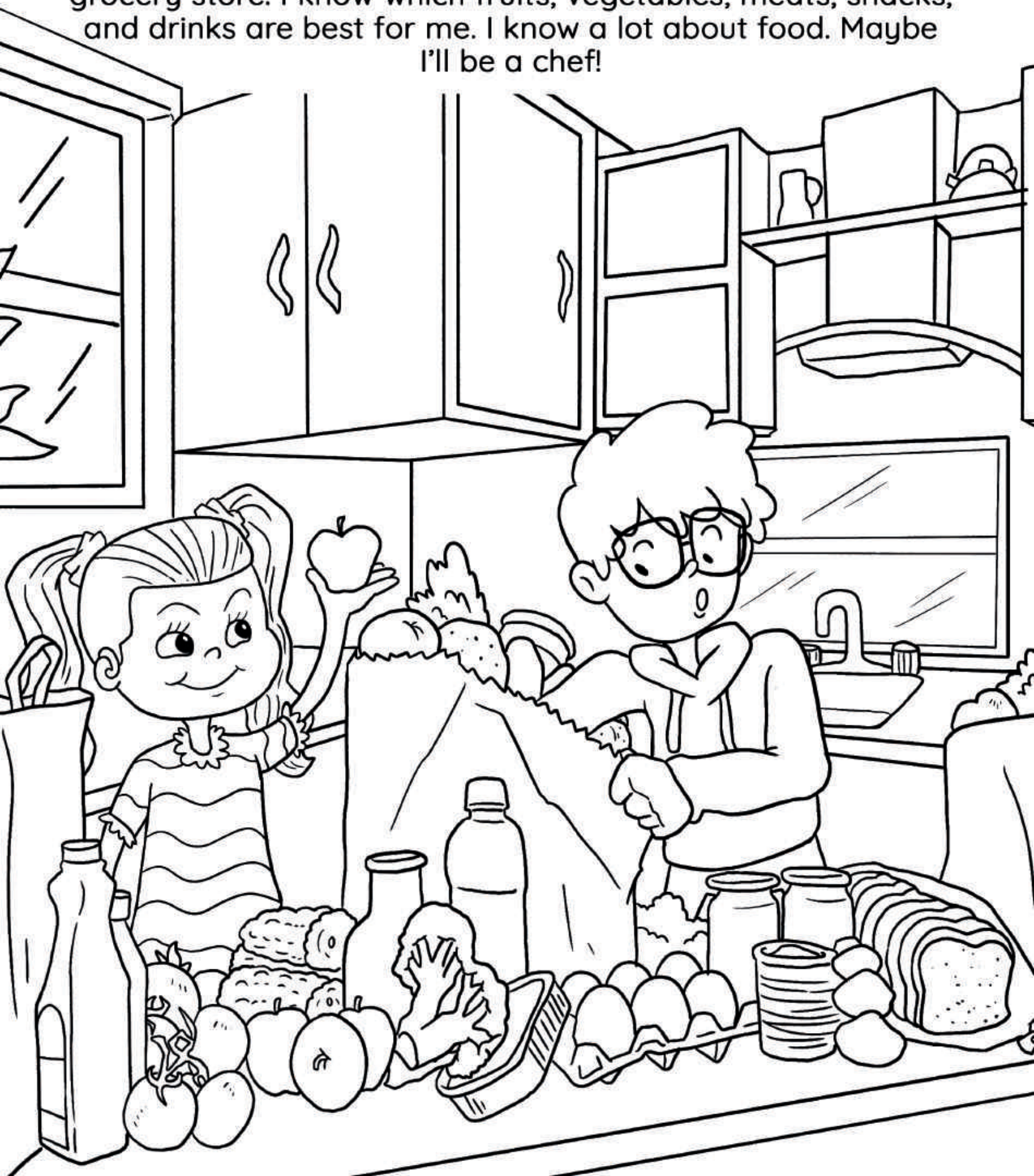


My kidneys have trouble doing their jobs. I take medicine every day to help keep my kidneys as healthy as possible. I take my pill at night because it can make me feel tired. I need to tell Dr. Carter if the medicine makes me feel dizzy or too tired during the day.

My dad and I talk about how we feel about living with a kidney disease that people can't see from the outside, but we know is there. When Sam broke his arm, everyone could see his cast. No one can see our kidneys struggling on the inside.

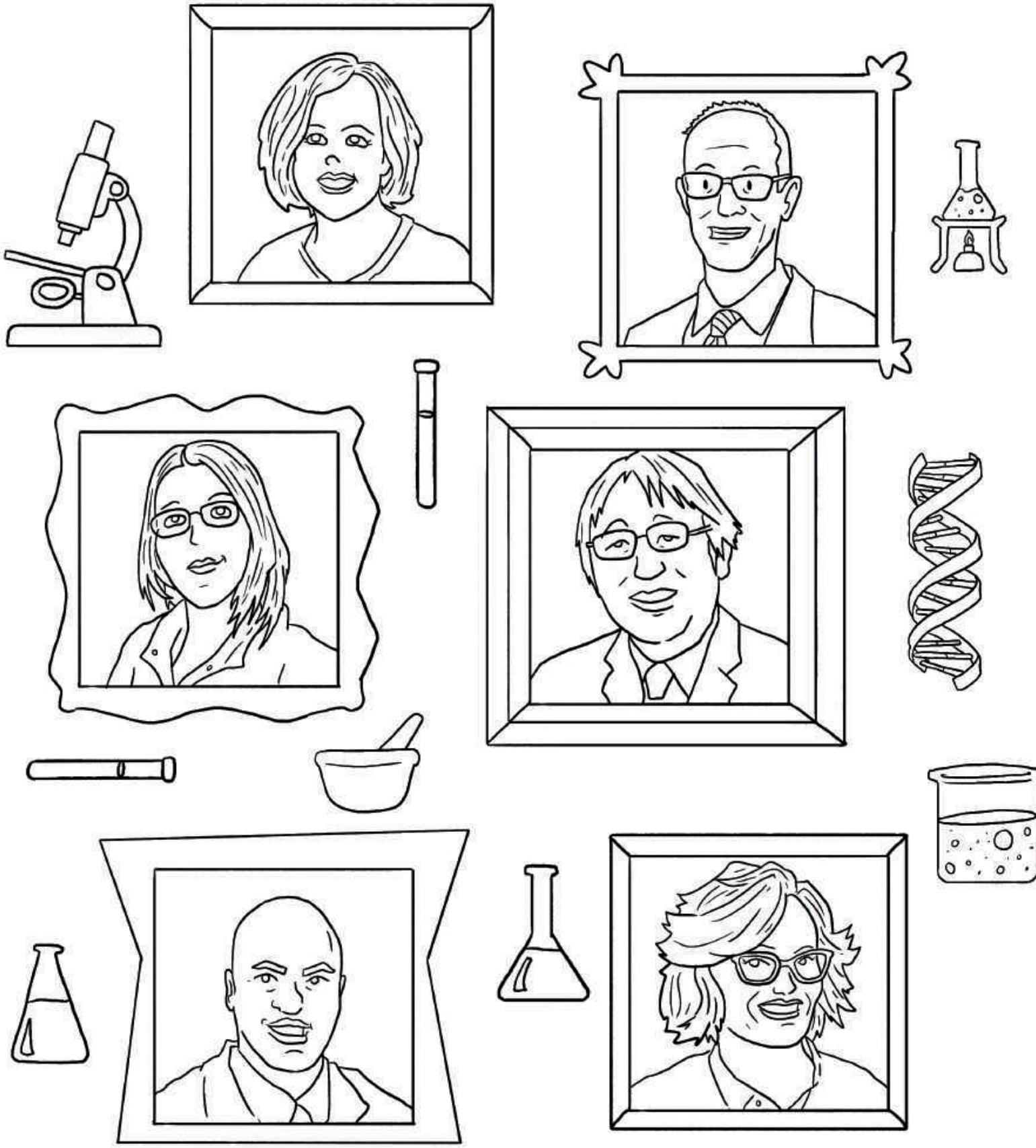
I know my family worries a little more about me. It's just because they love me. When I have questions, I ask my parents or my doctor.

I learned a healthy diet can help my kidneys. My parents have an app on their phone that shows them the right foods for me and my dad. They read all the food labels at the grocery store. I know which fruits, vegetables, meats, snacks, and drinks are best for me. I know a lot about food. Maybe I'll be a chef!

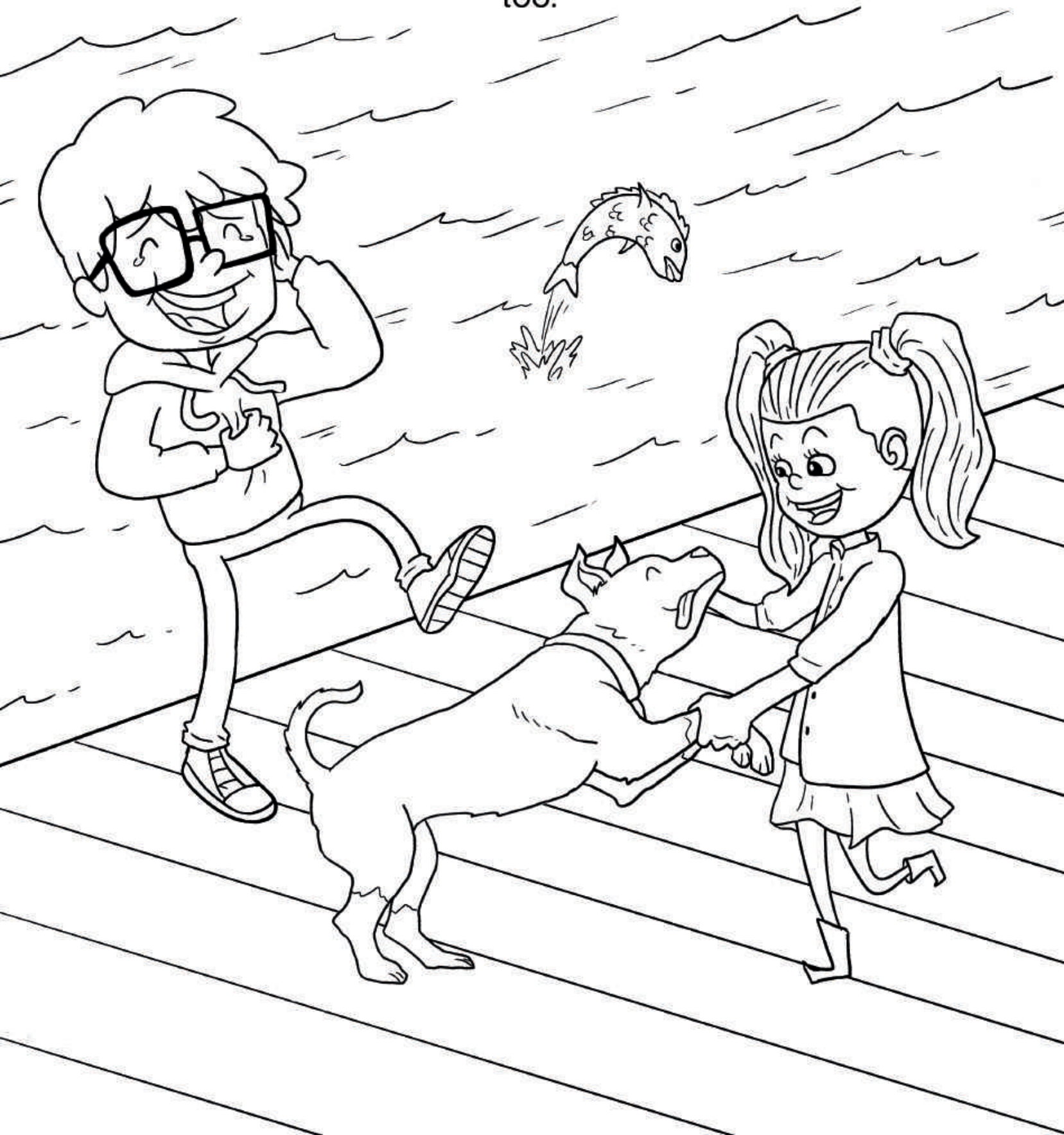


Guess what? I went to a meeting with other people with Alport syndrome. I met Grant. He is 10 and lives in another city. Grant wears blue hearing aids. He takes the same medicine I do. His family might come visit and go biking with us. It makes me feel less alone to meet other people who understand.

We learned there are people all over the world studying Alport syndrome and how to help our kidneys and hearing loss. Isn't that great? I feel hopeful for EVERYONE who has Alport syndrome.



Maybe one day I'll need someone to help me with a kidney like my Uncle Kevin did. Maybe not. Either way, I can choose to be happy. I will keep dancing, roller skating, playing with my dog, and laughing with Sam. I am learning to take good care of myself. I hope you are too.



Maybe one day I will help others with Alport syndrome know they are not alone.

Did you enjoy this coloring book and getting to know a bit about Annie and her family?

Sharing your favorite colored pages can help other families learn about Alport syndrome too! We will share some of them on our website.

With the permission and help of an adult, email a picture of your favorite colored in page or pages to info@alportsyndrome.org. Along with the photo, be sure to email us:

- your first name (no last names will be listed on the website)
- your age
- the state where you live

You could win a prize from Alport Syndrome Foundation for sharing your art!

You can also share your thoughts about this coloring book with us. We are always open to your ideas and look forward to hearing from you.

Alport Syndrome Foundation
info@alportsyndrome.org

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On behalf of the Alport syndrome community of patients and families, we extend our gratitude to these sponsor companies that are investing their scientific and financial resources into improving methods to diagnose and treat Alport syndrome. There is hope to change our families' stories. We appreciate this investment in our future.
– Alport Syndrome Foundation 2021

For more information about Alport syndrome for patients, families, medical providers and researchers, visit www.alportsyndrome.org.

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