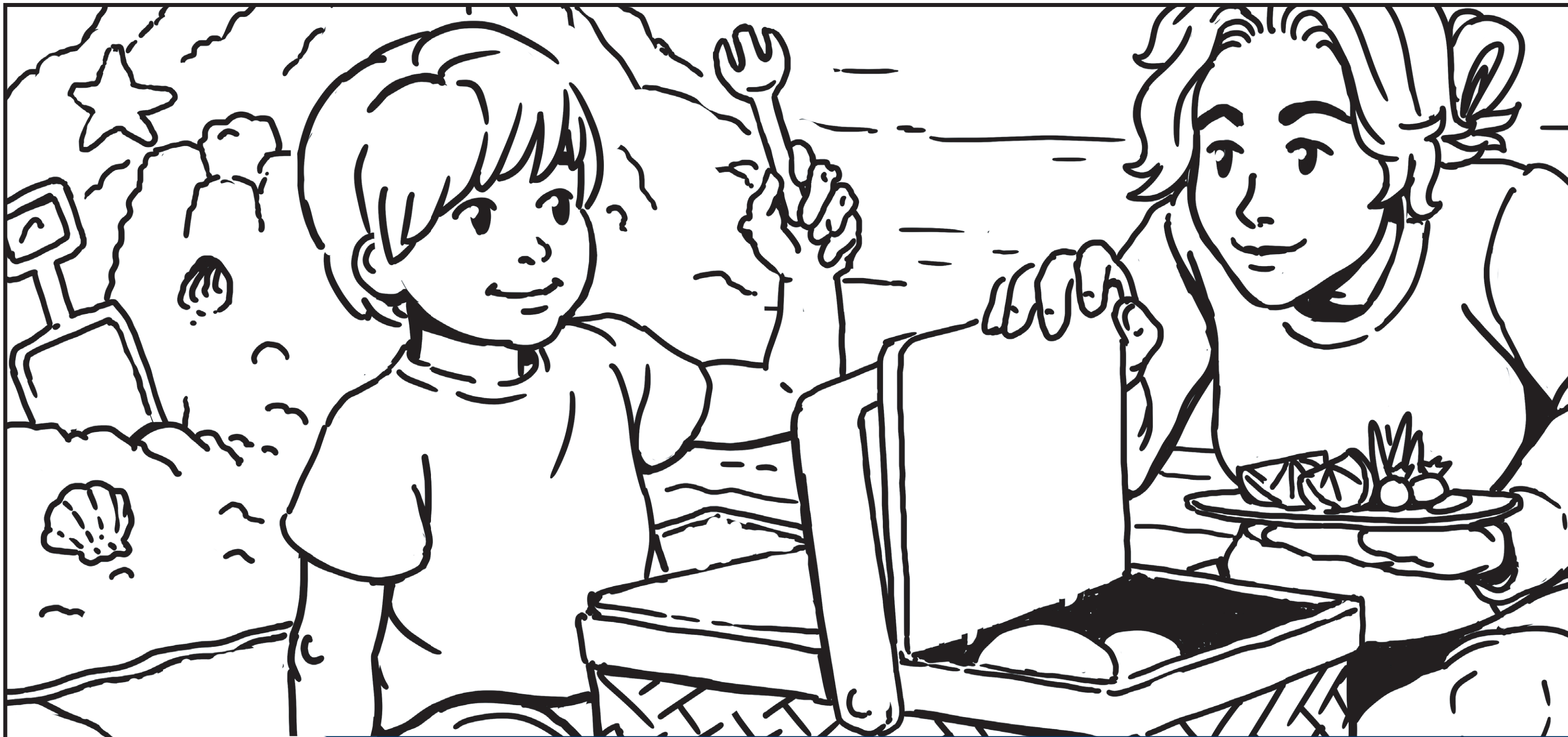




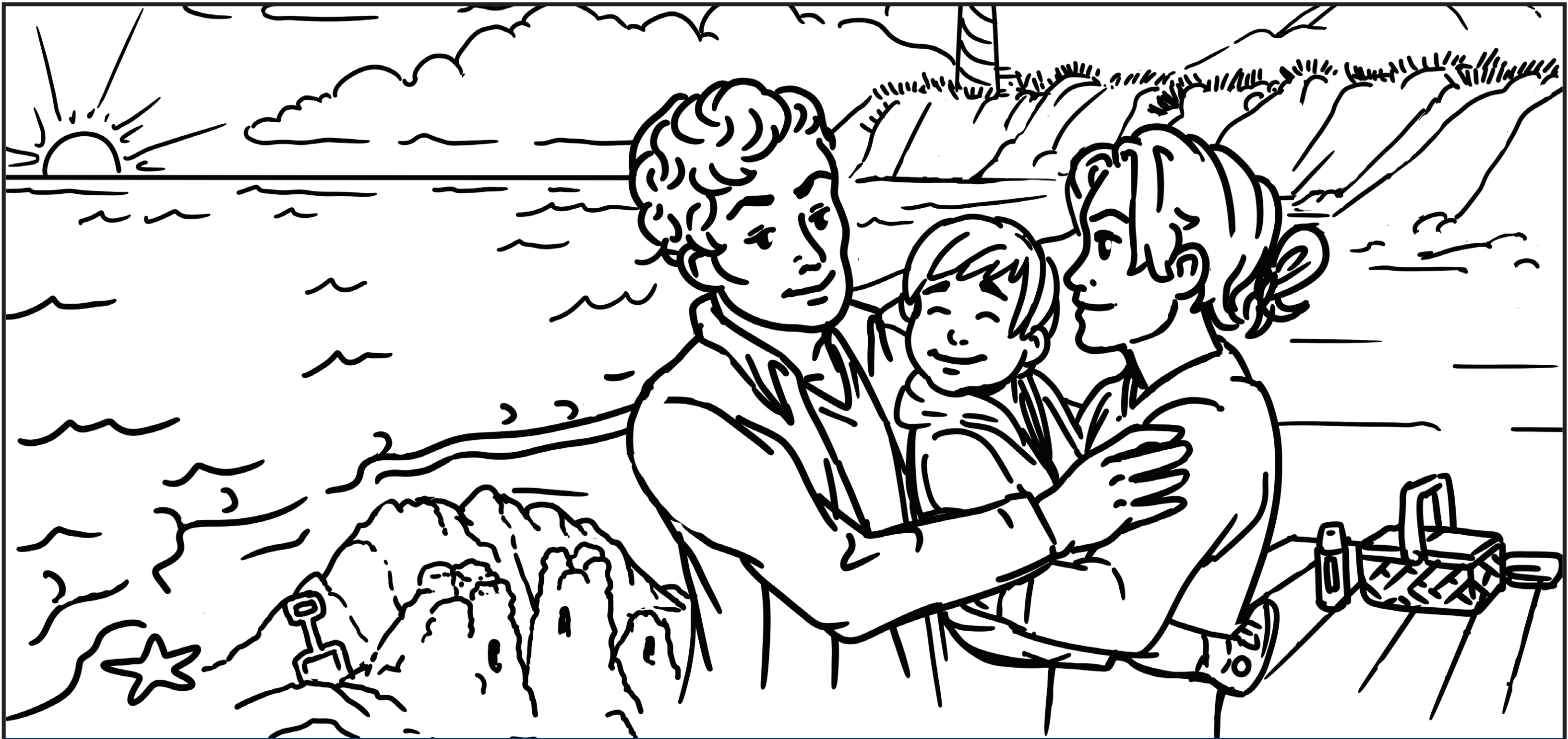
ADVANCE

CLINICAL STUDY FOR FARBER DISEASE

**A COLORING BOOK
FOR KIDS**

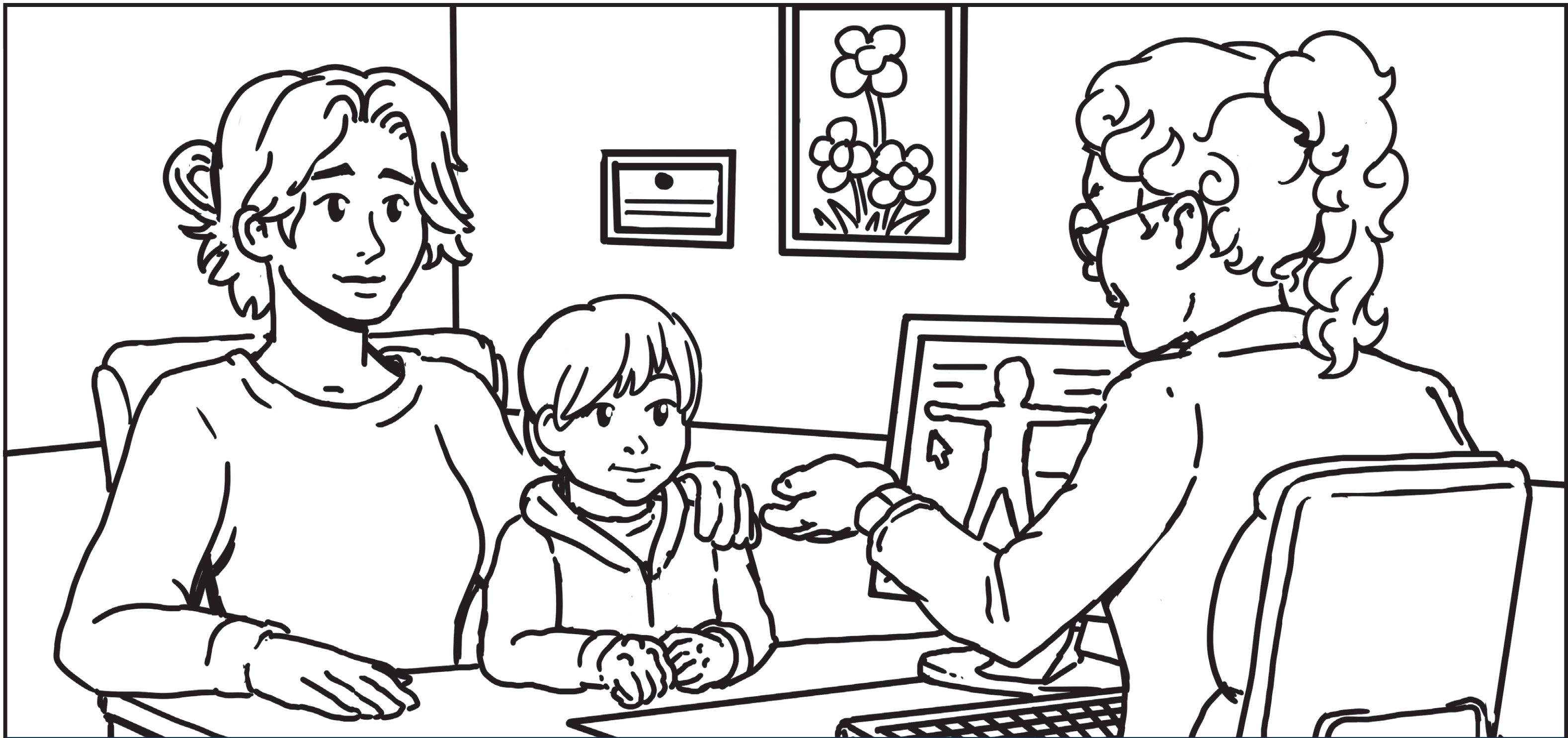


People like you and other kids who join studies help doctors learn more about new medicines.



The ADVANCE study may be for kids like you who are living with Farber disease.

Some kids living with Farber disease have bumps under their skin that hurt and can make it hard to walk, jump, and play.



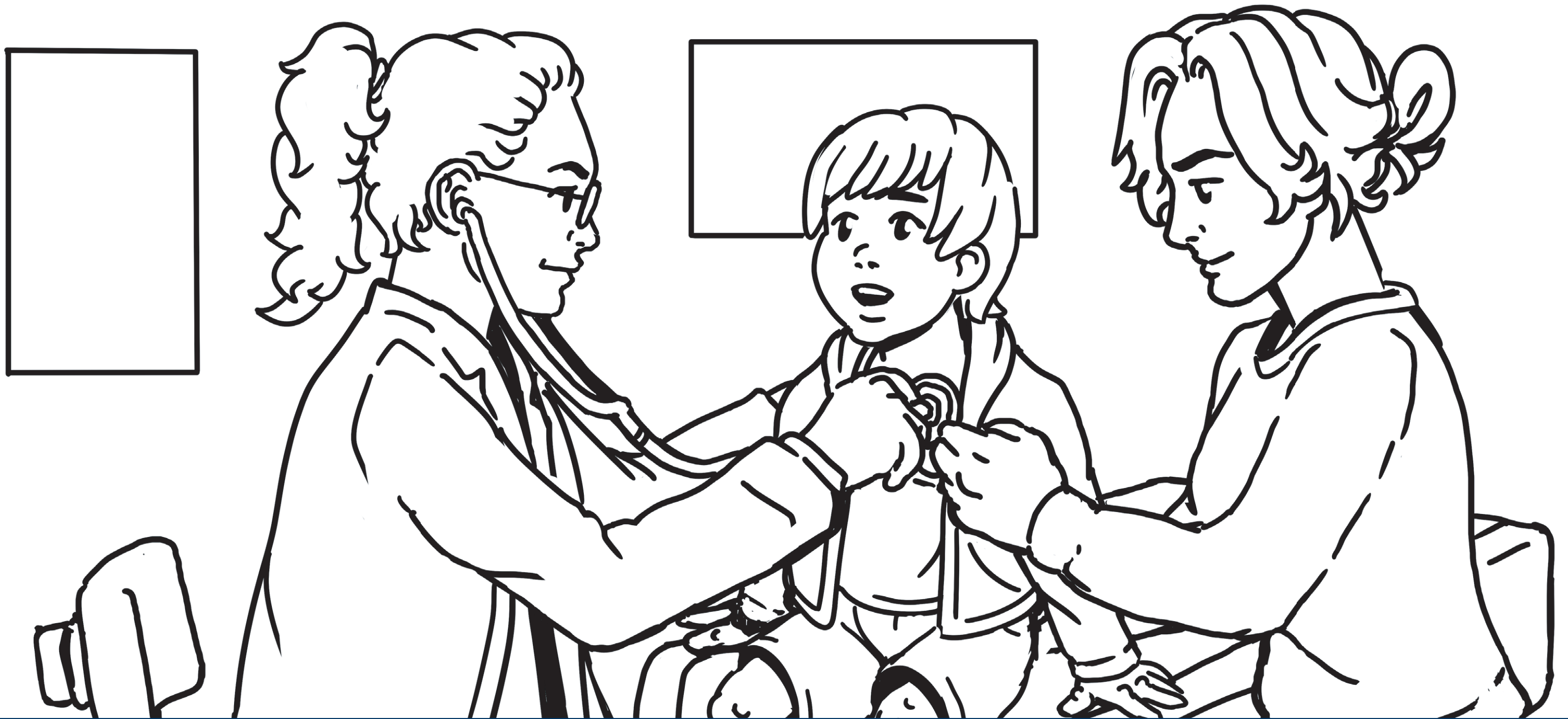
The ADVANCE study doctors want to learn if a study medicine might stop Farber disease from getting worse and might make things like moving around easier than before. An ADVANCE study doctor will take care of you and answer your questions.

The study will last 7 months. During that time, you will have 15 visits with your ADVANCE study doctor that will take all day and sometimes two days.



WHAT TO EXPECT AT MOST VISITS

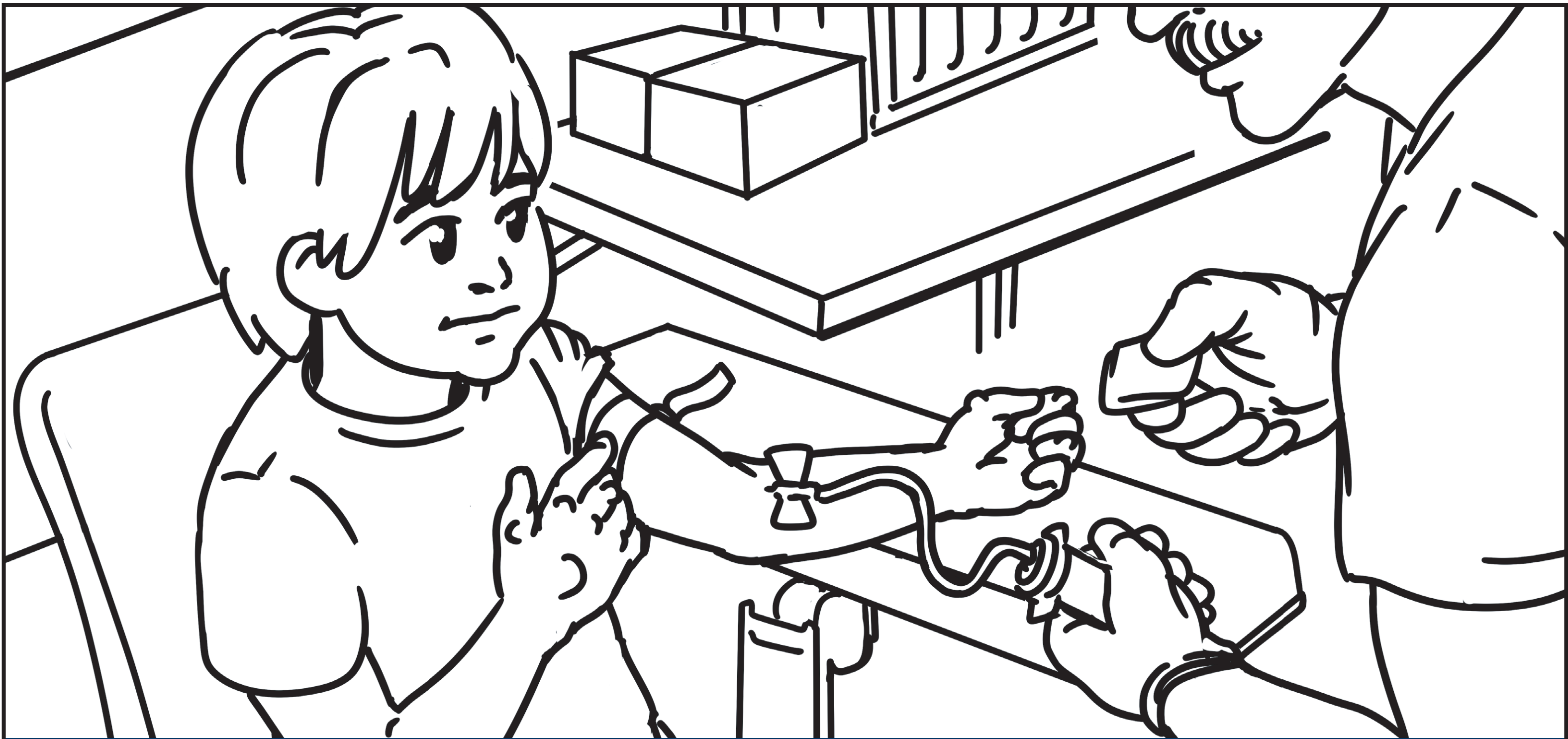
- ▲ Get a check up
- ▲ Answer questions about how you are feeling
- ▲ Give some blood
- ▲ Take the medicine



GET A CHECK-UP

The study doctor will check your height and weight, listen to your chest, and feel your belly, just like at a regular doctor's visit.

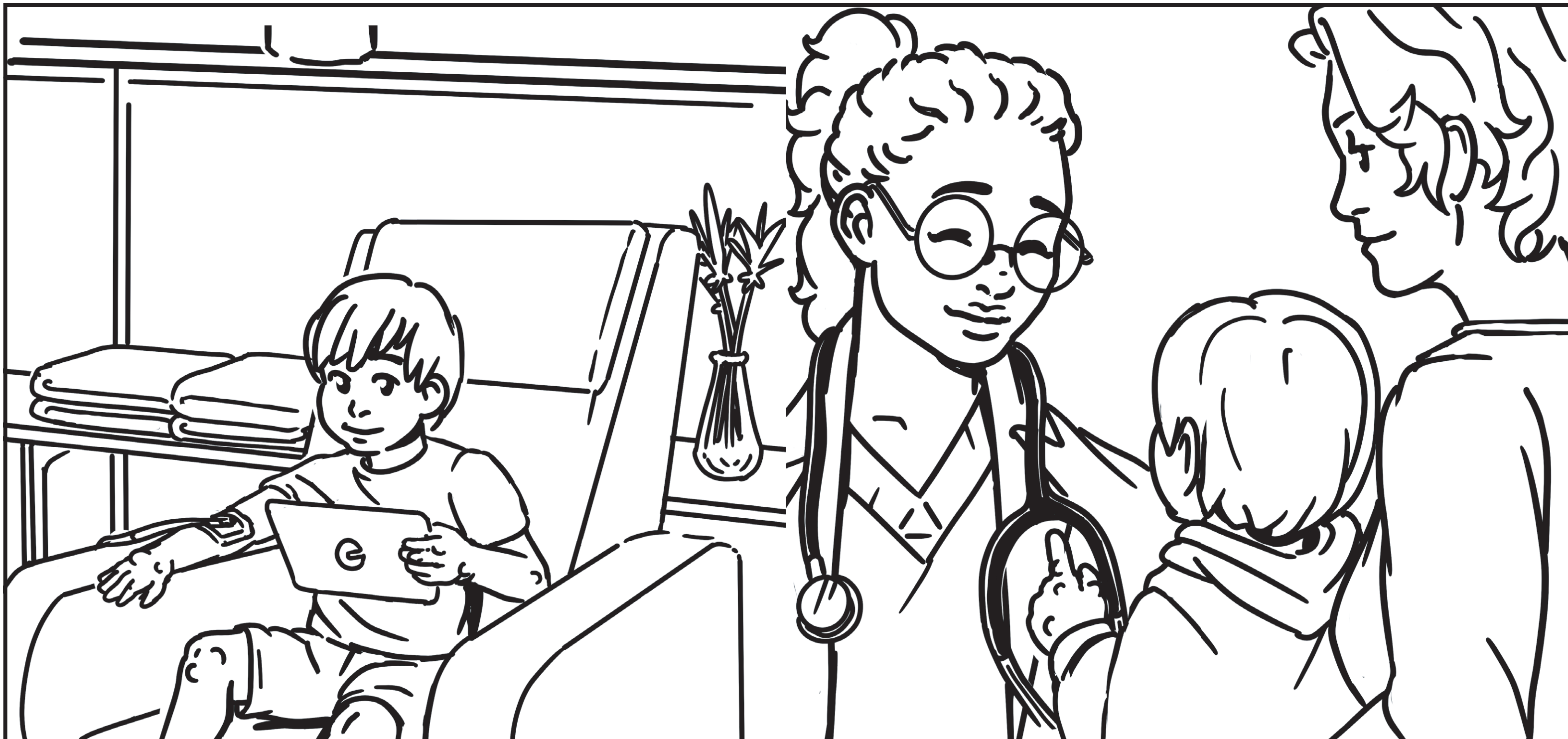
The doctor will also ask questions about how you feel, take your temperature, and put a cuff around your arm to take your blood pressure.



GIVE SOME BLOOD

You will need to give a blood sample at some visits. Your doctor might ask you to not eat or drink anything the morning before these visits.

When the needle goes into your arm, it might hurt for a few seconds.



TAKE THE MEDICINE

The ADVANCE study medicine will be given by infusion, which means it will drip slowly through a tiny plastic tube in your arm or another place the doctor recommends. It might hurt for a few seconds when it goes in your arm the first time. It takes about 3 1/2 hours for the infusion. You can read a book or watch a movie during this time!

TAKE A BREAK!

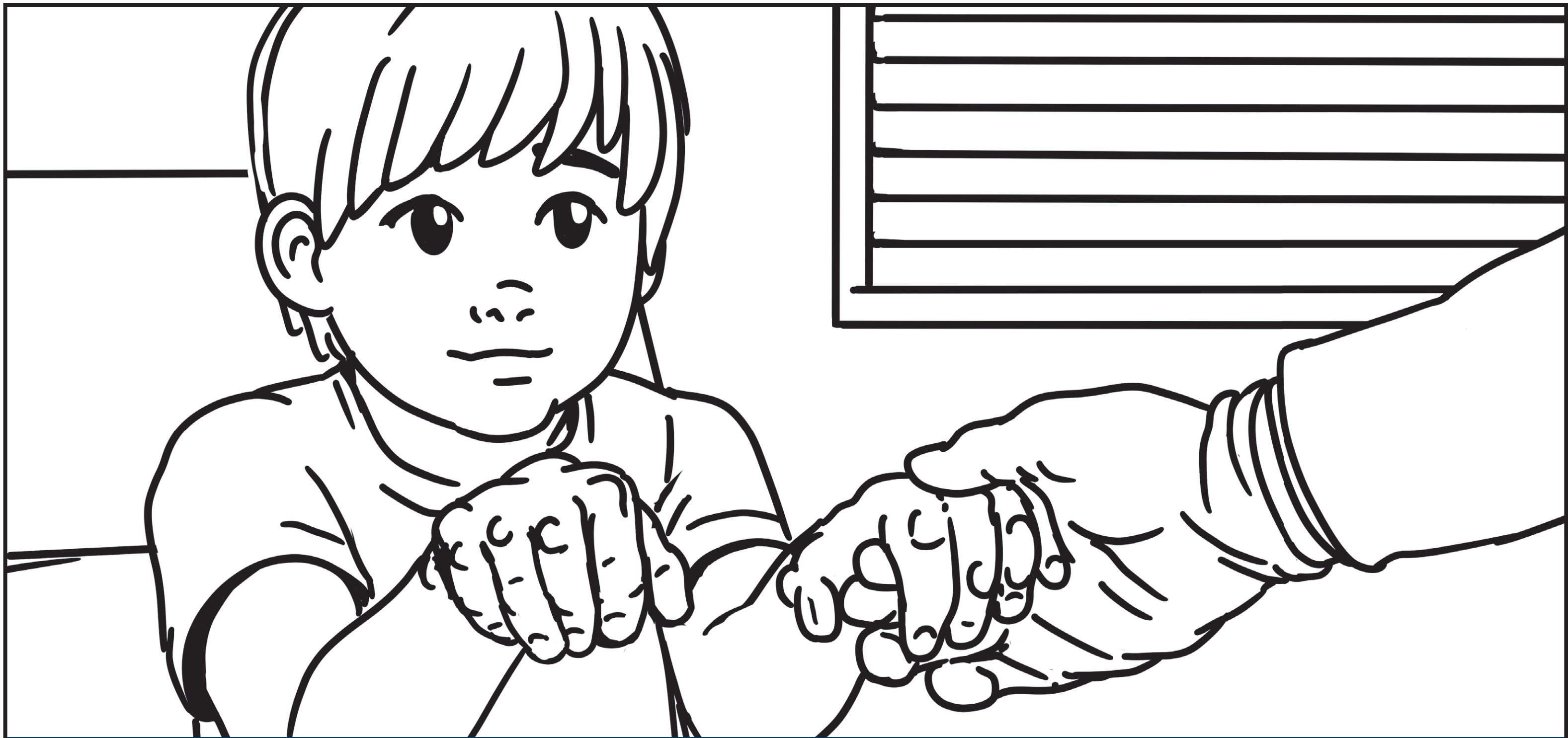
Tell your doctor how you are feeling and if you need a break during your visits. Your doctor is there to help you understand what to expect and to help you feel okay.



WHAT TO EXPECT AT SOME VISITS

At some of your visits, the study doctors might do other tests to see if there are any changes since you started taking the new medicine...

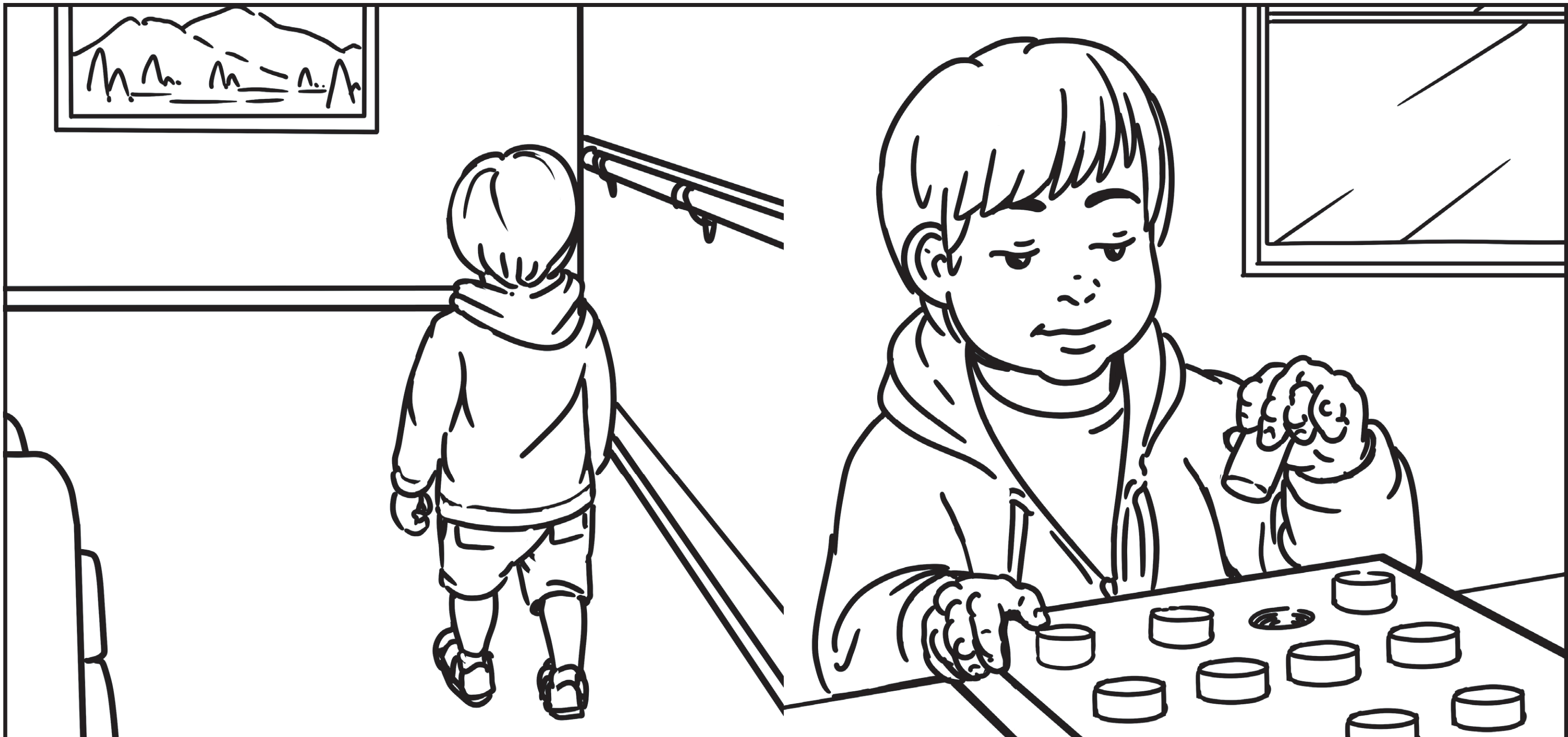
- ▲ Show your bumps
- ▲ Take a walk
- ▲ Use your hands
- ▲ Breathe into a machine
- ▲ Have an ultrasound
- ▲ Move your arms and legs
- ▲ Get an electrocardiogram (ECG)
- ▲ Take a urine test (for some girls only)



SHOW YOUR BUMPS

The bumps will get a lot of attention! The study doctor will circle, measure, and take photos of the bumps so they can see if they change over time.

If you have a lot of bumps this might take a while.
Tell your doctor if you need a break.

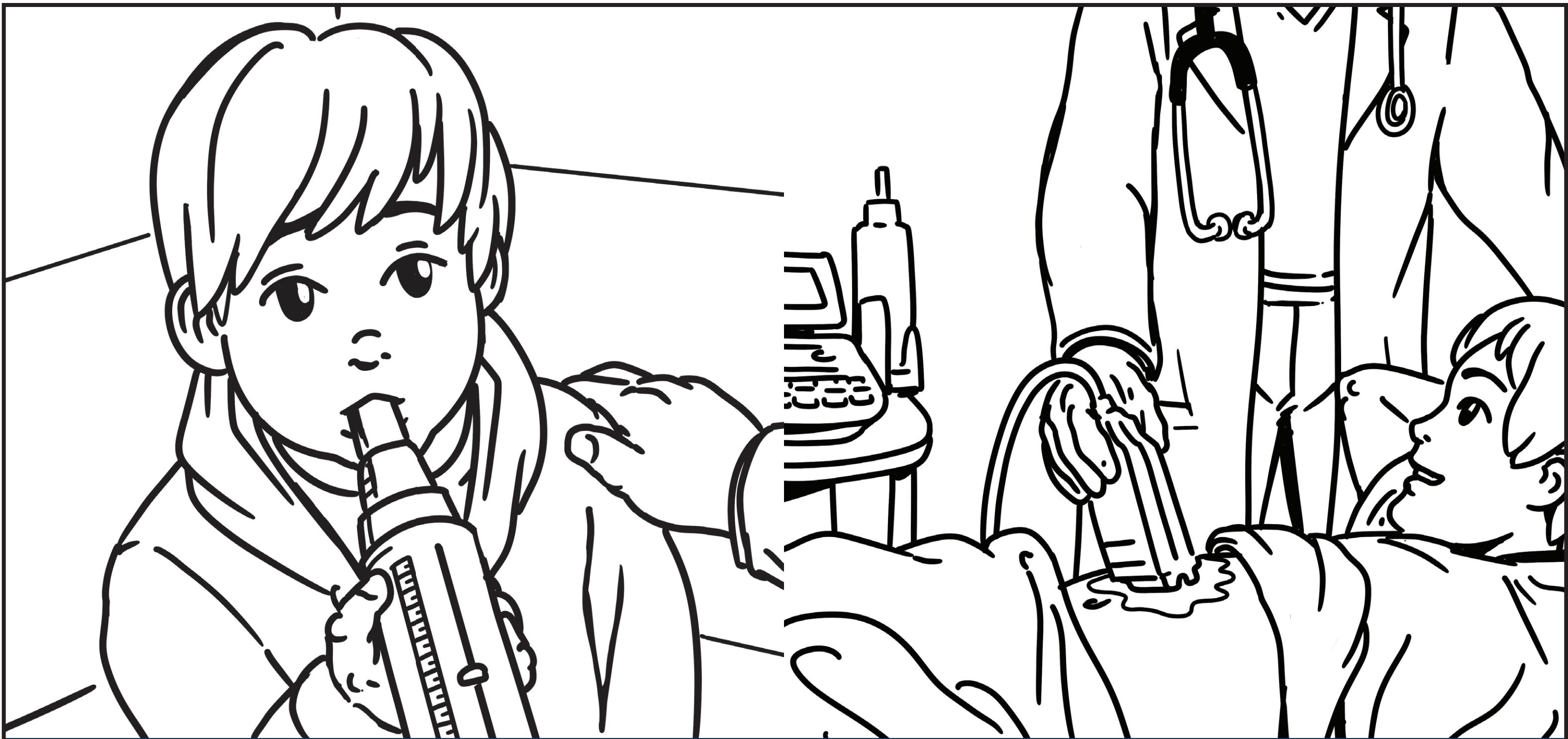


TAKE A WALK

You may be asked to do a walking test on a little track inside the hospital. You will wear a sensor on your finger to measure how fast your heart beats while you walk.

USE YOUR HANDS

The ADVANCE study doctor may ask you to put pegs into holes in a board to see how well you are able to use your hands.

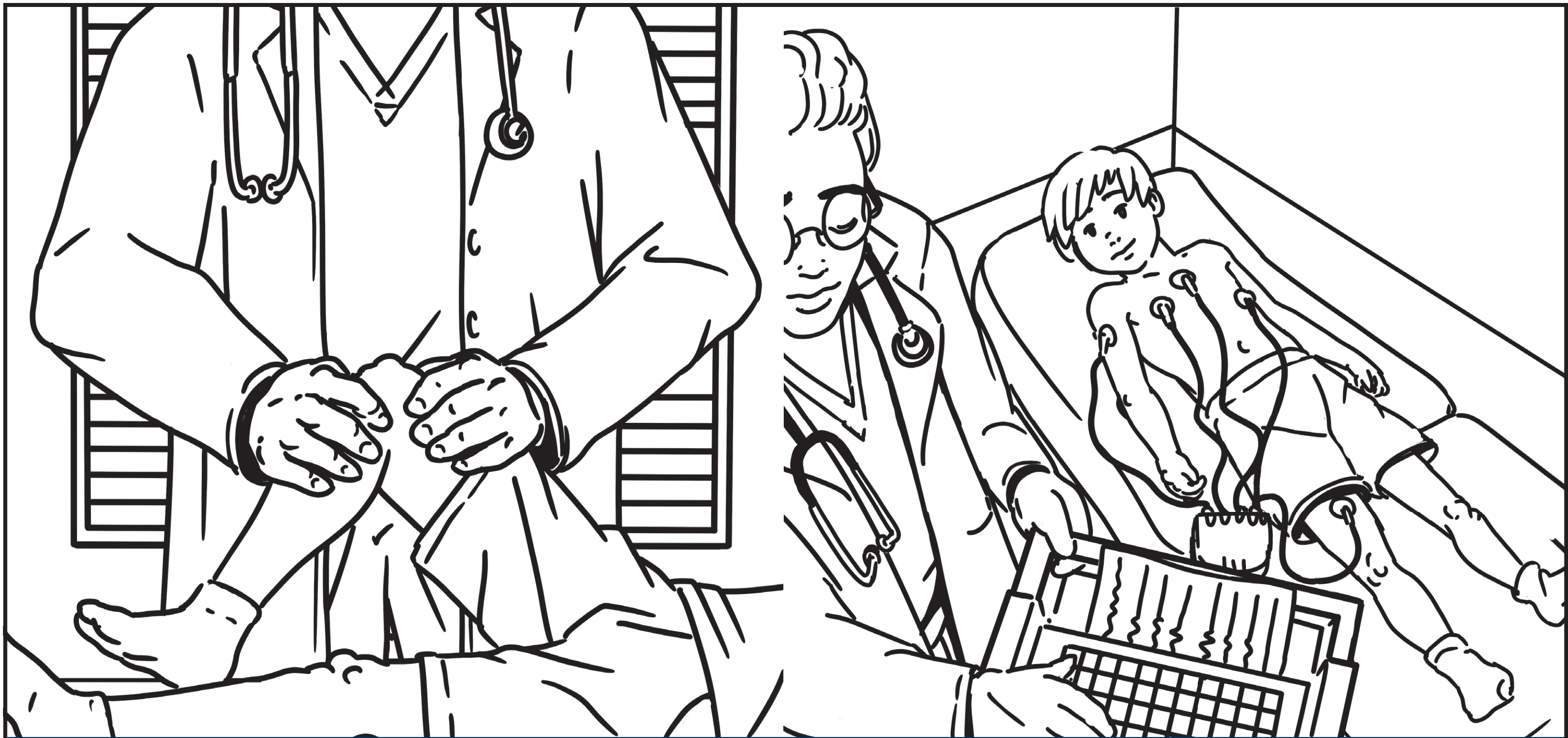


BREATHE INTO A MACHINE

You may be asked to do a breathing test. This test will measure how much air your lungs can breathe in and out. The study doctor will show you how to breathe in and out of a tube. You might have to hold your nose.

HAVE AN ULTRASOUND

The ultrasound will give the study team a picture of your liver and spleen. The study team will put some jelly on your belly so the instrument can slide over your skin while it takes pictures. It will not hurt, but the jelly might be cold.



MOVE YOUR ARMS AND LEGS

The study team will gently measure how easily and how far your wrists, shoulders, hips, knees, and ankles can move.



























































































GET AN ELECTROCARDIOGRAM (ECG)

An ECG measures how your heart is beating. Small stickers that hold wires will be placed on your chest, arms, and legs. When the ECG is done, taking the stickers off will feel a little like taking off a bandage.

WHAT TO EXPECT AT YOUR ADVANCE STUDY VISITS

During your study visits, fill in the  as you go!

(Please note: This is not an official tracking document for the study. It is for study participant use only.)

Visit	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	Final	
Week	0	2	4	6	8	10	12	14	16	18	20	22	24	26	28		
WHAT TO EXPECT MOST VISITS																	
Check up																	
Lots of questions																	
Give some blood																	
Take the medicine																	
WHAT TO EXPECT AT YOUR ADVANCE STUDY VISITS																	
Show your bumps																	
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