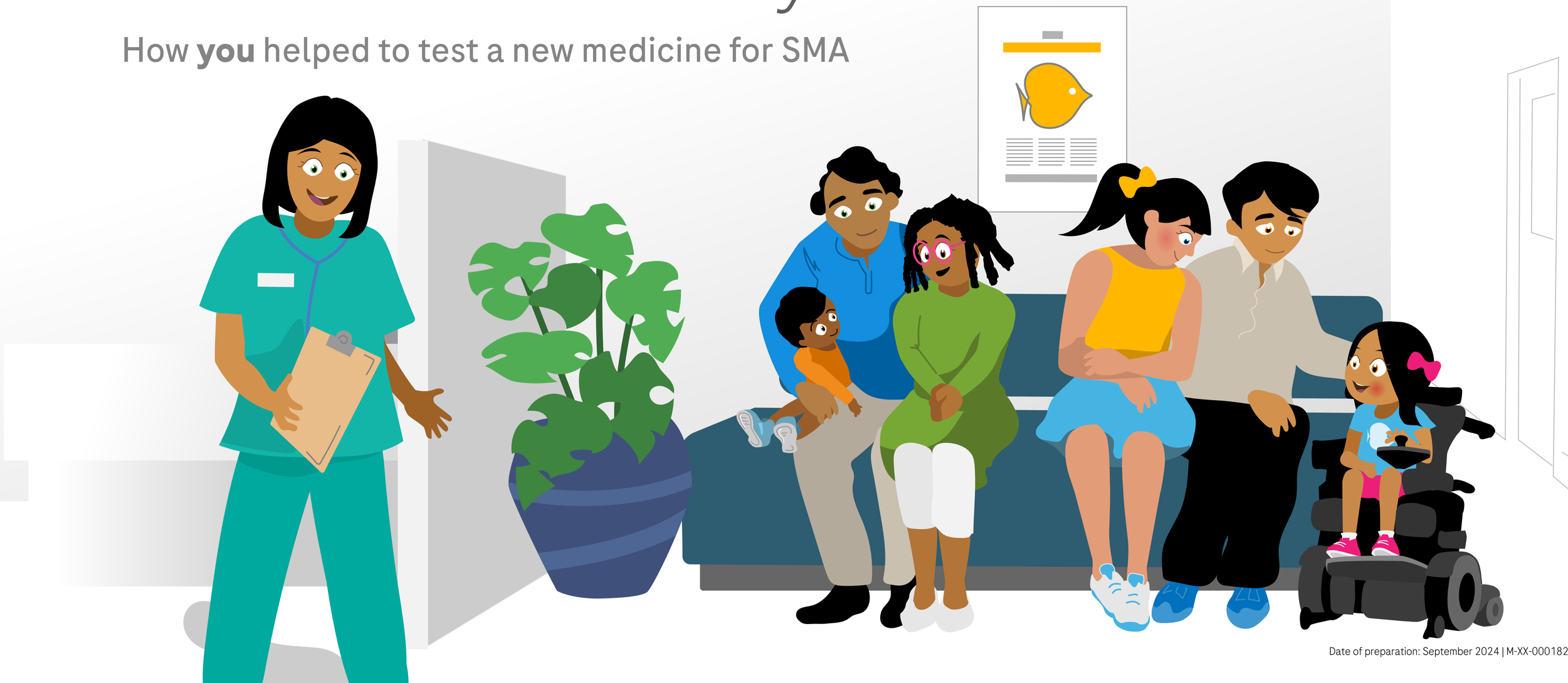
The SUNFISH *study*

How **you** helped to test a new medicine for SMA



Date of preparation: September 2024 | M-XX-00018240

You were born with a condition called SMA.

You may also hear it being called spinal muscular atrophy.

SMA makes your muscles weak and makes it harder for you to move.

You might find it hard to do things like eating or getting dressed.

Everyone with SMA has different things they find hard to do.

When you were younger, your doctor and family decided that you should take part in a research study.

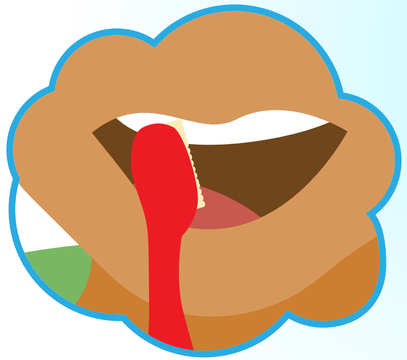
Research studies help doctors find out more about conditions like SMA.

The research study
was called SUNFISH.
It tested if a new medicine
could help people with SMA.

You were given the
medicine every day at home.

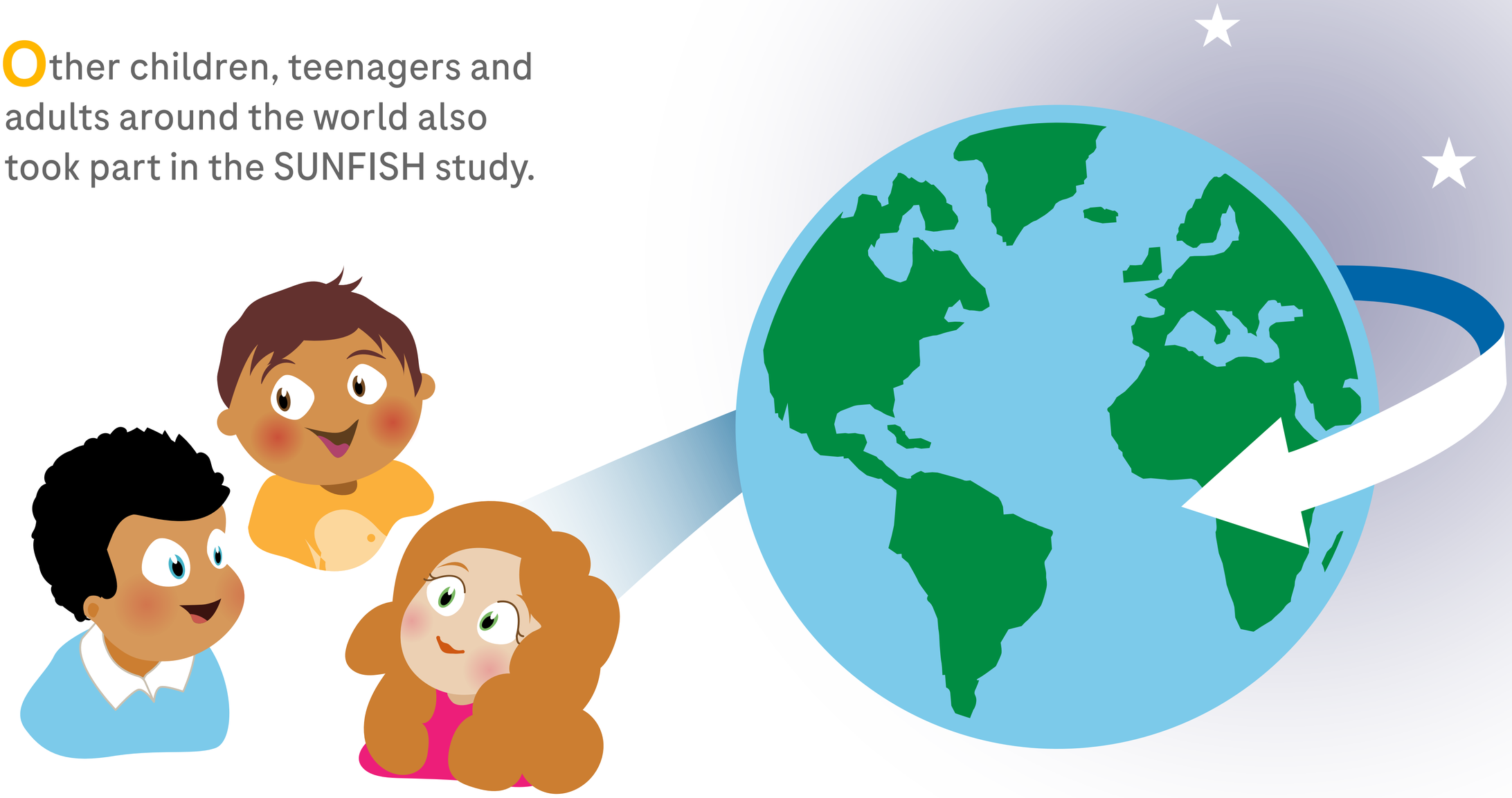
You visited the doctor many times while you were in the SUNFISH study.

Each time, your doctor checked how well your muscles were working.



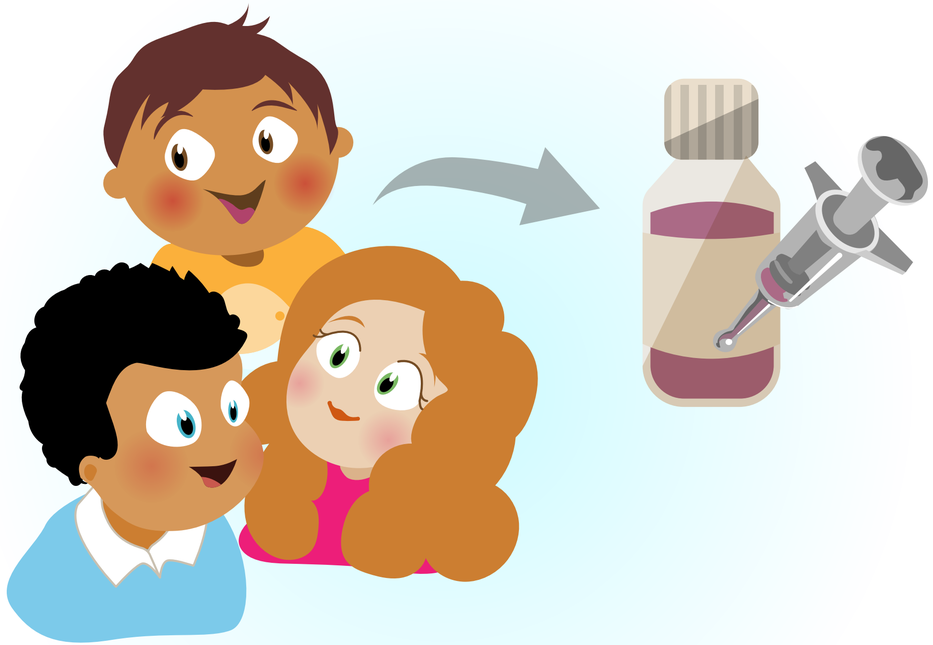
Your parents told the doctor how well you could do things like eating, brushing your teeth, and getting dressed.

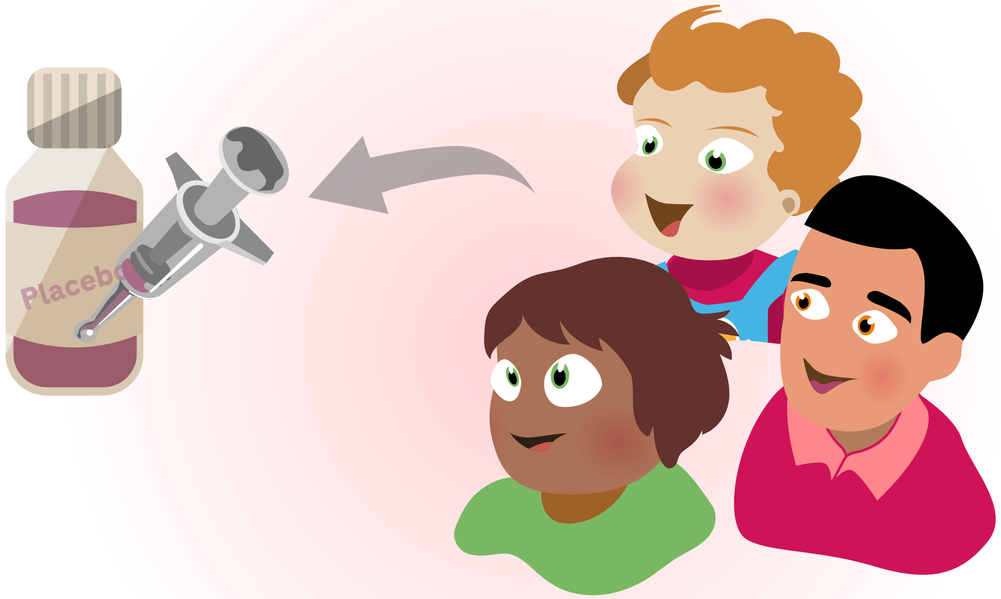
Other children, teenagers and adults around the world also took part in the SUNFISH study.



The SUNFISH study had two groups.

Group 1 took the study medicine.

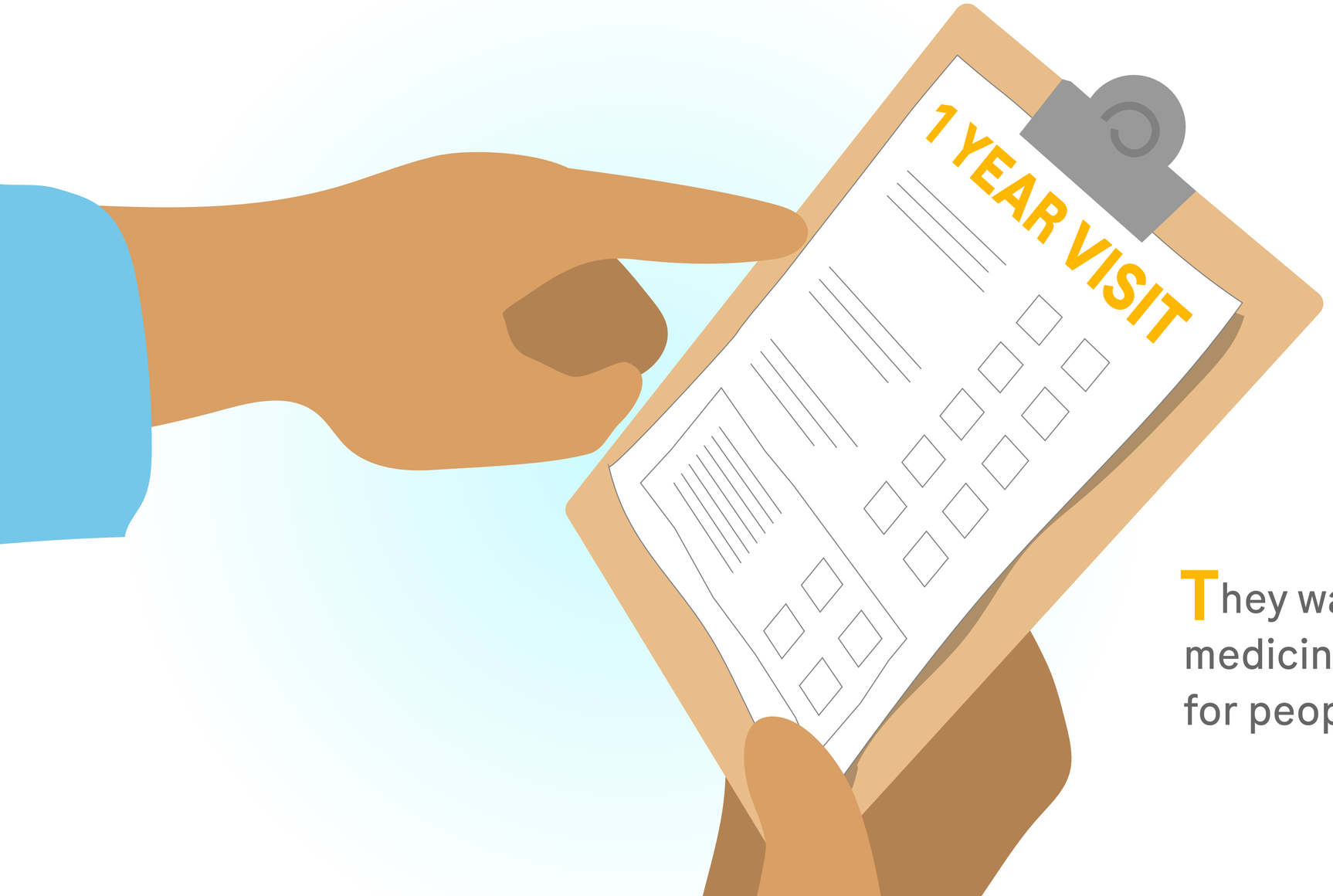




Group 2 took a dummy medicine.
This is also called a placebo.

It looks and tastes the same as the study medicine but has no effect on the body.

After one year, doctors checked how well everyone's muscles were working and compared the two groups.



They wanted to know if the study medicine worked and if it was safe for people to take.

The people who took the study medicine could move better than the people who took the dummy medicine.

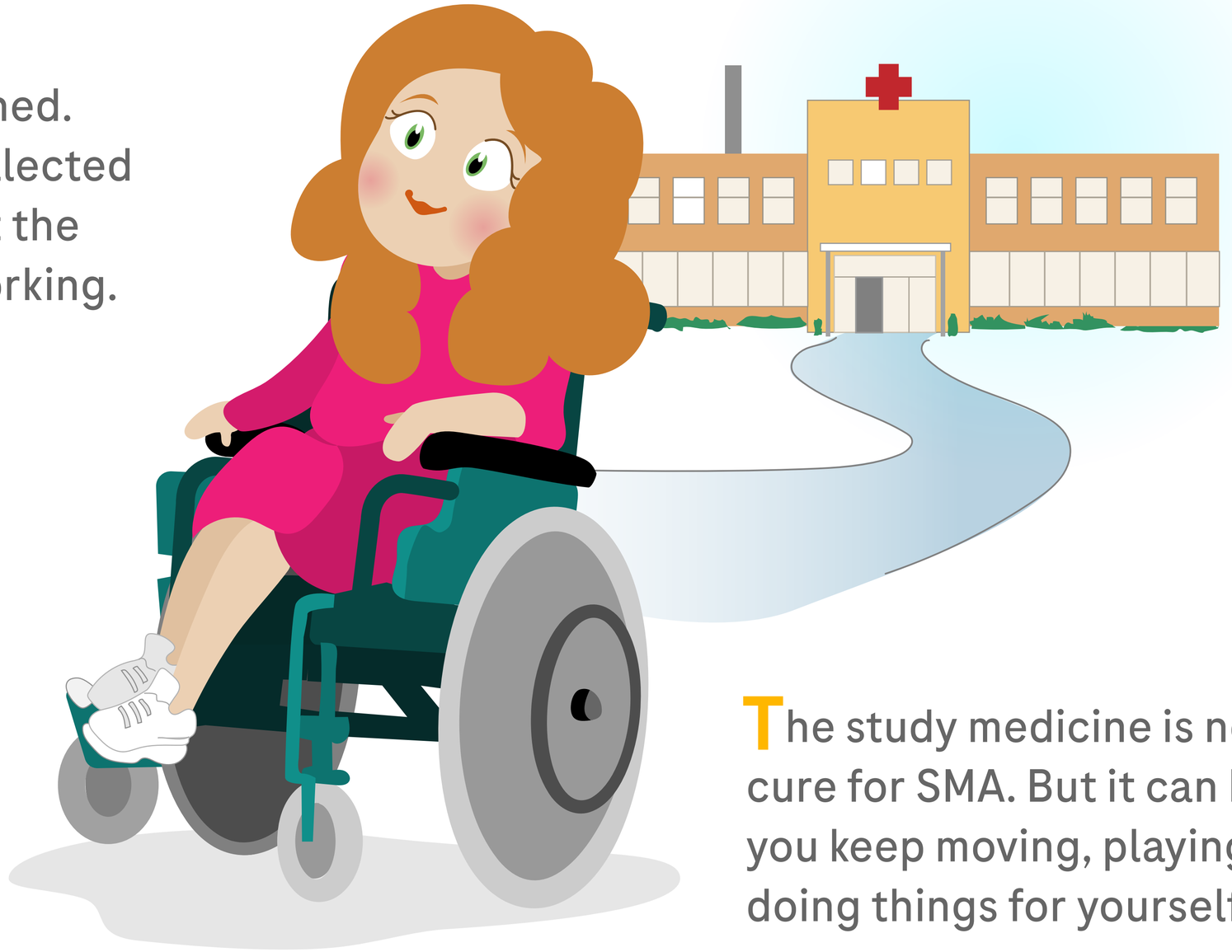
They needed less help from their parents to do things like getting dressed.

After one year, everyone who received the dummy medicine was given the study medicine instead.

The SUNFISH study followed people taking the medicine for up to 5 years.

The study is now finished. The information we collected helped us to learn that the study medicine was working.

Thanks to the study findings, many people can take this medicine to treat their SMA.



The study medicine is not a cure for SMA. But it can help you keep moving, playing, and doing things for yourself.

Thank you for taking part in this study!

If you have any questions, please ask your parents or your doctor.

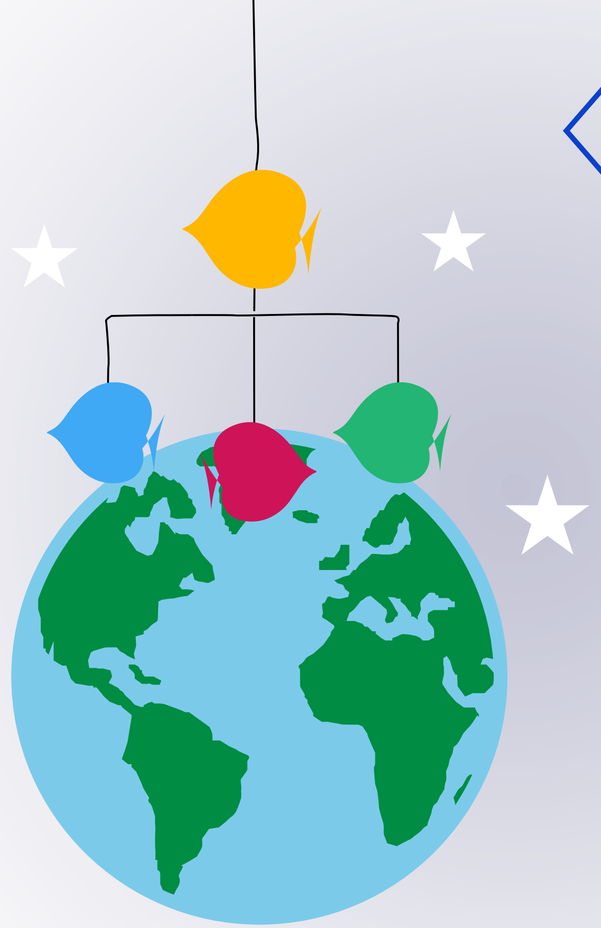
This is a summary of the clinical trial known as SUNFISH (NCT02908685).

We would like to take the opportunity to thank all the patients, families, healthcare professionals and patient organisations who contributed to the success of the SUNFISH study. It was an immense privilege to be part of the journeys of all the families who made this study possible. Thank you.

If you or your child have taken part in this study and have any questions about the results, please speak with your doctor or other medical staff at your study site.

If you have any further questions, please contact a representative at your local Roche office.

F. Hoffmann-La Roche Grenzacherstrasse 124 CH-4070 Basel, Switzerland



Risdiplam (EVRYSDI®)▼ has been approved by the US Food and Drug Administration (FDA) for the treatment of pediatric and adult patients with SMA, and by the European Medicines Agency (EMA) for the treatment of individuals with Type 1, 2 or 3 SMA or one to four copies of the *SMN2* gene.

▼ This compound is subject to additional monitoring. This will allow quick identification of new safety information. Healthcare professionals are asked to report any suspected adverse reactions via their national reporting system. This compound and its use may not be approved in your country. This information is presented only for purposes of providing a general overview of clinical trials and should not be construed as a recommendation for use of any product for unapproved uses.

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