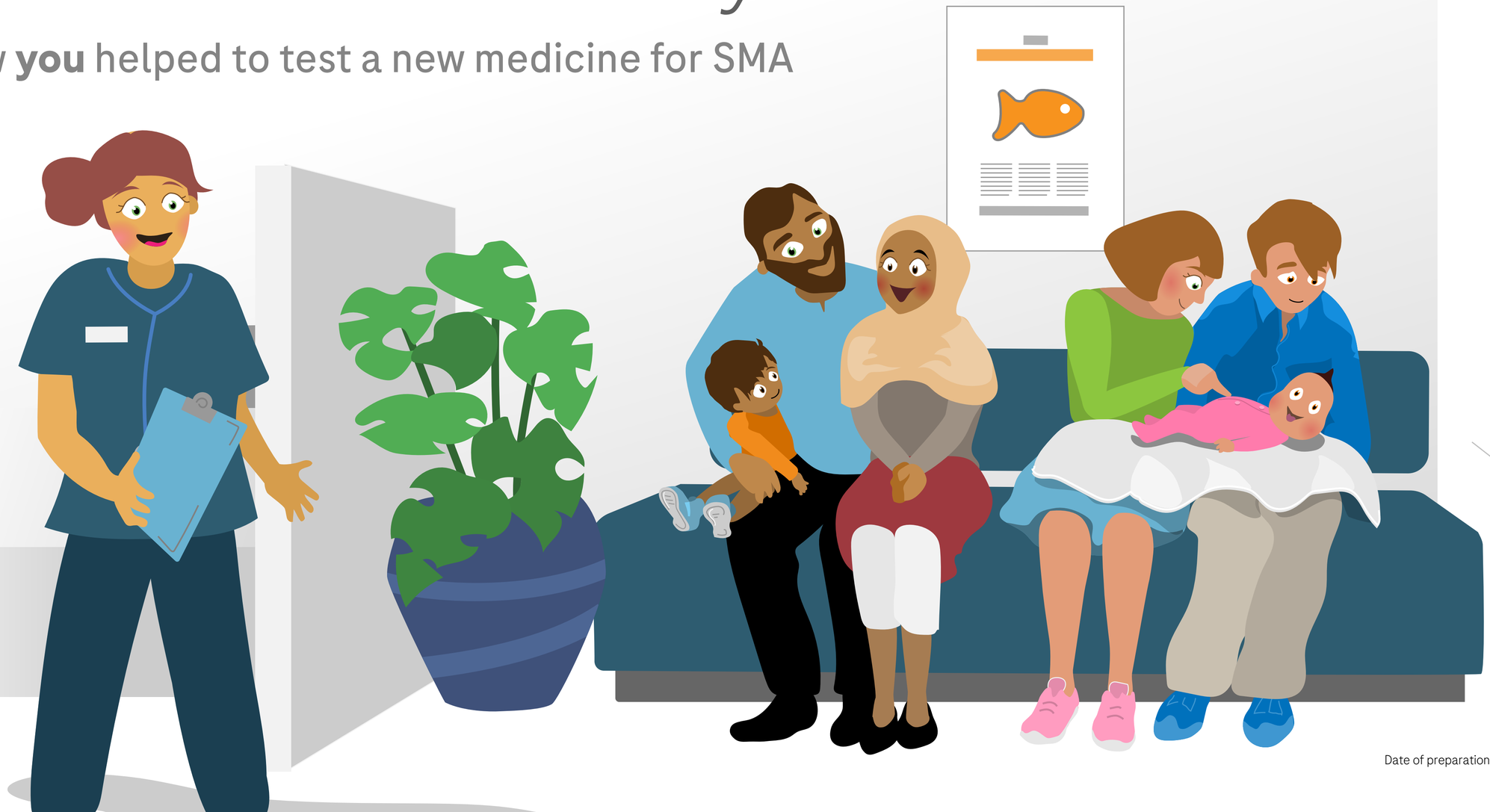
The FIREFISH *study*

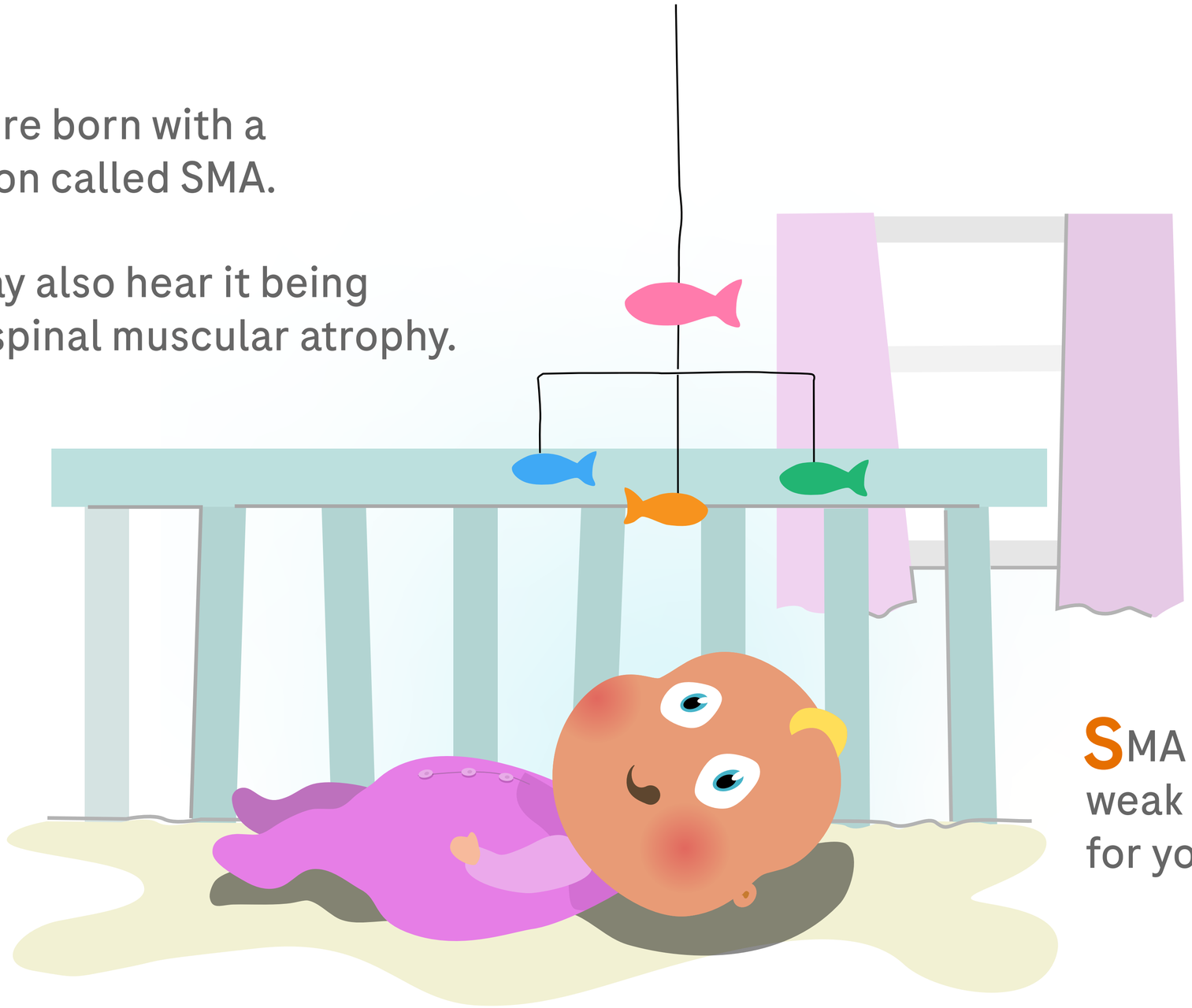
How **you** helped to test a new medicine for SMA



Date of preparation: September 2024 | M-XX-00018073

You were born with a condition called SMA.

You may also hear it being called spinal muscular atrophy.

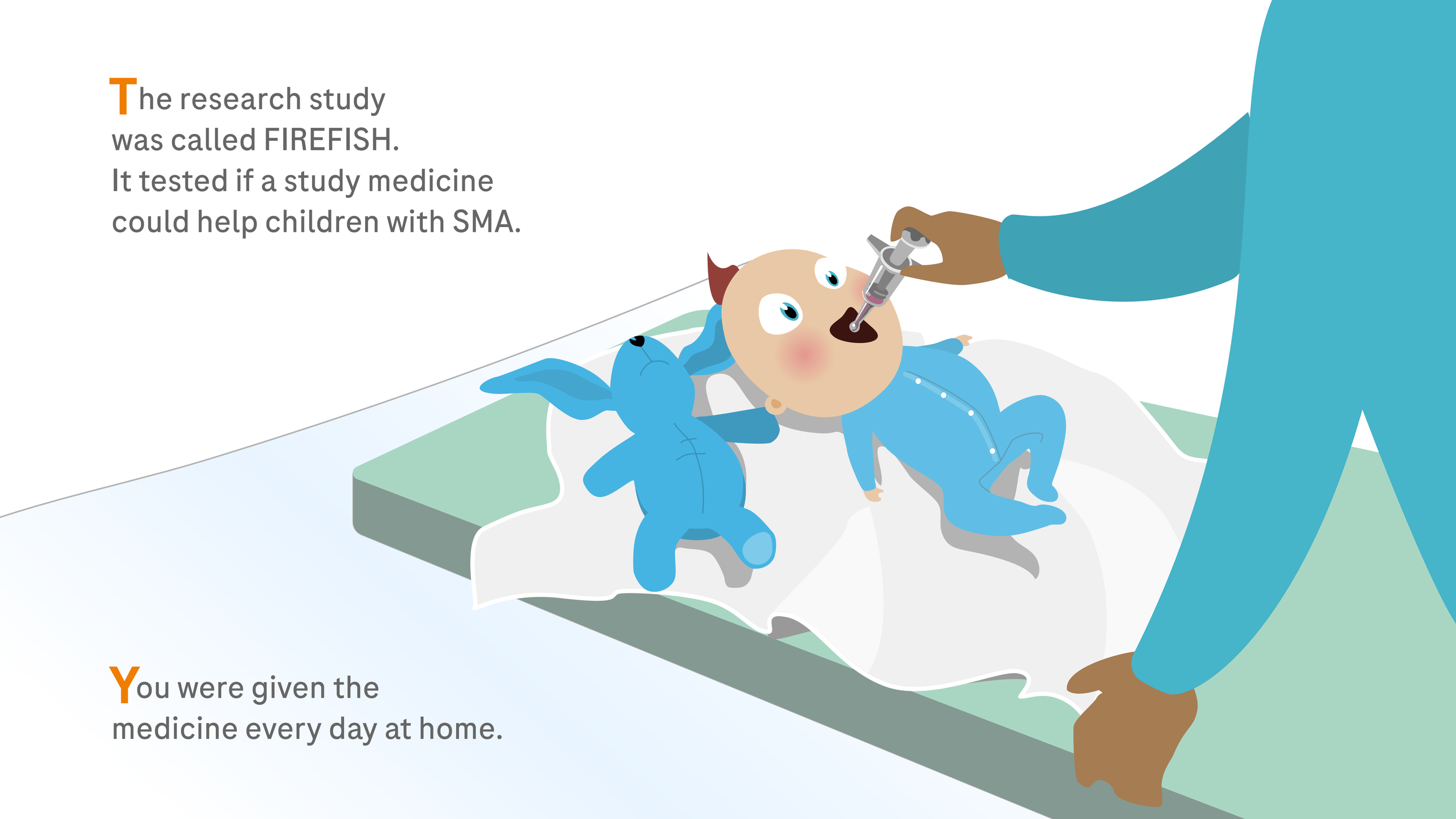


SMA makes your muscles weak and makes it harder for you to move.

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 FIREFISH.
It tested if a study medicine
could help children with SMA.



You were given the
medicine every day at home.

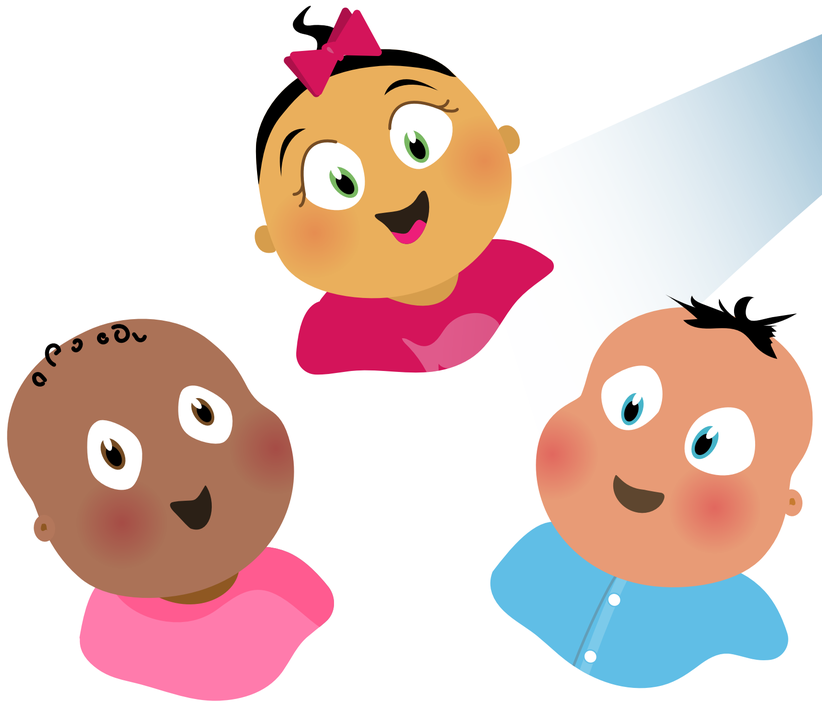
You went to see your doctors many times.

The doctors measured how well you were growing and moving.

They also wanted to see if you had any other effects from taking the study medicine.

Other babies with SMA around the world also took part in the study.

Their doctors gave them the study medicine too.



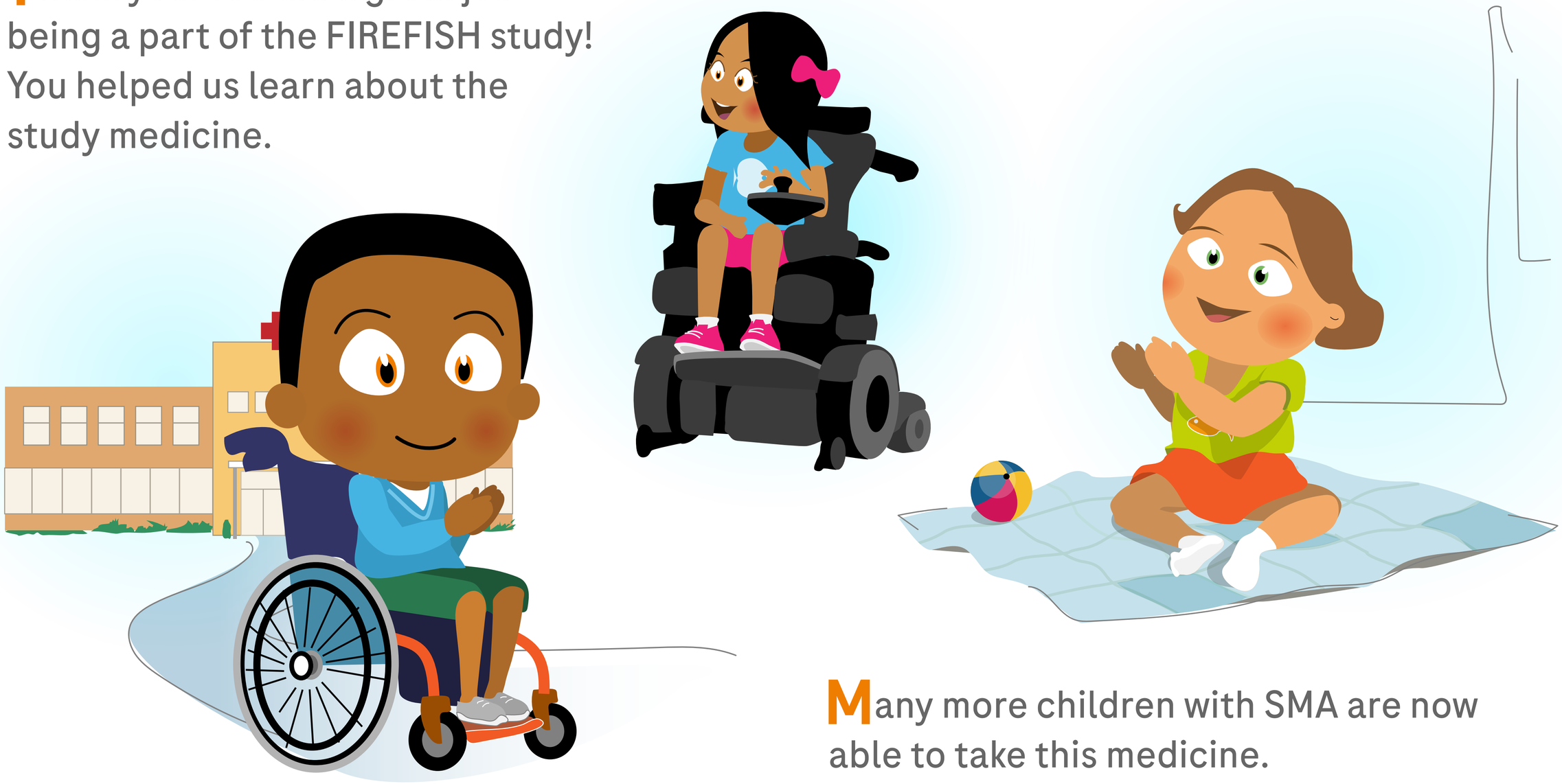
You and other children were part of the FIREFISH study for at least five years.

Most of the children were able to move better during the study.

Many of the children were able to swallow their food.

Many of the children were able to sit without any help.

Thank you. You did a great job being a part of the FIREFISH study! You helped us learn about the study medicine.



Many more children with SMA are now able to take this medicine.

Thank you for taking part in this study!

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

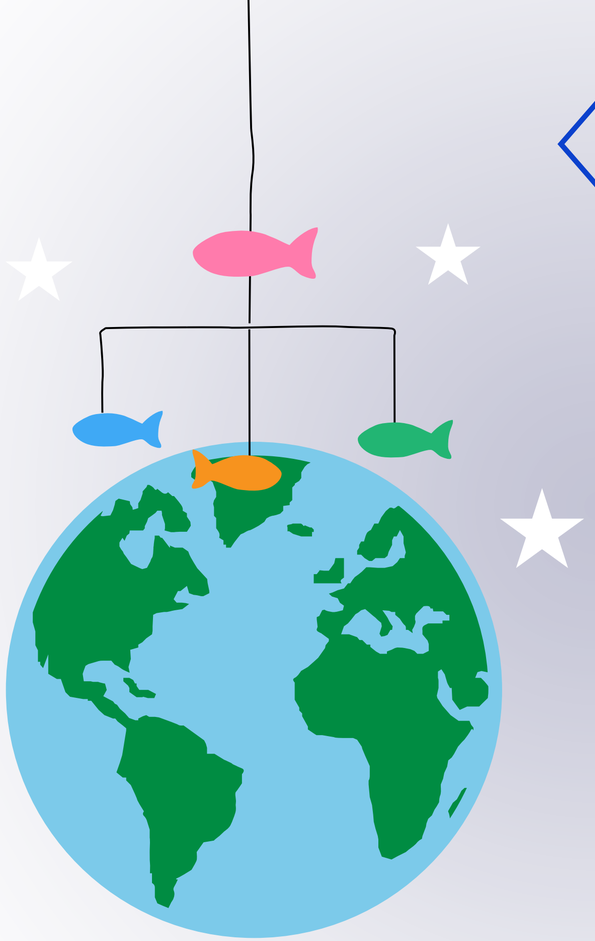
This is a summary of the clinical trial known as FIREFISH (NCT02913482).

At the end of the FIREFISH study we would like to take the opportunity to thank all the patients, families, healthcare professionals and patient organizations who contributed to the success of the trial. 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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