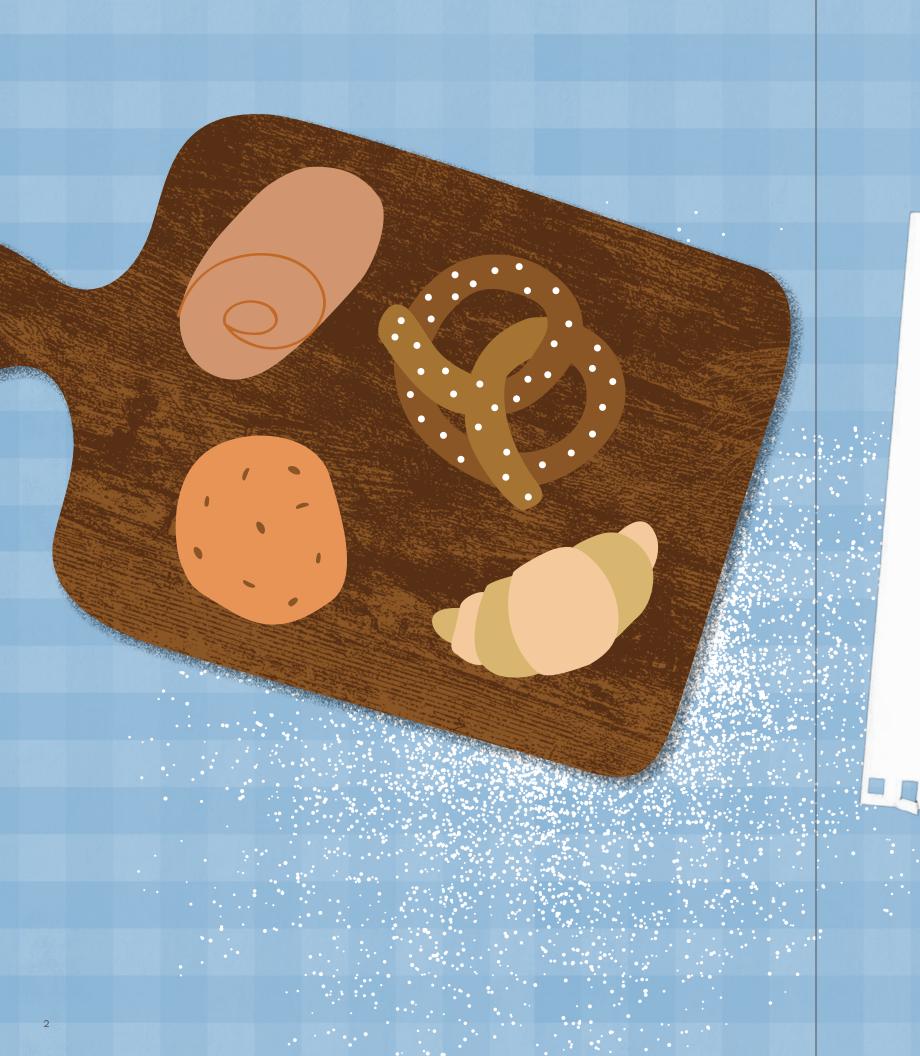


READER'S COMPANION





FOR ADULTS READING TO YOUNGER AUDIENCES



Did you know there are *hundreds* of different types of bread, each with their own set of ingredients? While recipes outline the ingredients and the amount used, every baker makes it uniquely theirs.

Just like bread, people grow up with different experiences, and it's these "ingredients" that make each person one of a kind.

These ingredients can look like family and friends, or even schools and communities. They can come from moments of hardship just as much as from moments of joy.

For kids with achondroplasia, it's no different—they **adapt**, **innovate**, and **learn** on the fly, as any child will.

Every page of the Rising Love book is full of details that can be used to start a conversation around different aspects of growing up with achondroplasia.

There are adaptations, family and sibling dynamics, and visual metaphors to explore with your child, their friend group or school, and others in your family's community.

Using this material as a guide will help you turn Rising Love into an **educational experience**, providing more detail around the condition of achondroplasia, including metaphors, conversation starters, and activities to help explain and engage with audiences of all ages.





Meet Sofia

8 years old

"The best part about people is getting to show them I care!"

Personality

Sofia loves animals and helping others. She is most comfortable in her home where it's quiet and she can spend time with her mom.

Mother

34 years old Does not have achondroplasia.

Talking Points



Family

Sofia's mom tries to provide a supportive environment to help Sofia build independence and confidence in her ability to adapt how and when Sofia feels it's necessary.



Adaptations

Sofia also has many different types of adaptations throughout her home. Stools, low furniture, light switches, and other items can help people with achondroplasia stay independent in a world that's usually made specifically for people of average stature.



Specific Challenges: Sleep Apnea

Sofia has achondroplasia, which causes the bones in her face to grow in a different way. Sometimes, this can make it difficult for air to get to her lungs, so she uses a machine made to help her breathe while she sleeps. This is called a CPAP or BiPAP machine.



Unique!

Only 1 of every 25,000 kids is born with achondroplasia! That means Sofia is 1 of only around 250,000 people in the world!



Meet Leo 10 years old

"Hy brother is the coolest person I know! After Grandma."

Personality

Leo loves reading, his grandma, and playing football with his older brother, Matt. He gets anxious sometimes and can worry, but Matt has experience dealing with anxiety, so both have learned ways to support one another.

Brother - Matt

Adaptations

16 years old Has achondroplasia.

Father

40 years old Does not have achondroplasia.

Talking Points



Leo's older brother Matt has achondroplasia, but Leo and their dad do not. Did you know 80% of kids with achondroplasia are born to parents of average stature? It can be random!



Matt can drive with specific adaptations. A pillow for back support, a raised seat, and some pedal extenders can make getting around as accessible as it is for someone without achondroplasia.



Specific Challenges: Mental and Social Health

Mental and social health are just as important to children with achondroplasia as the management of physical health. Leo and Matt are affected by anxiety differently, but Matt can help Leo by teaching him techniques for self-care that he learned when he wrestles with negative feelings.



Unique!

Just like daily routines, every family has a different style of adapting their homes for achondroplasia. Because Leo doesn't have achondroplasia, he finds himself having to adapt to the tools Matt uses!

Meet the Families

Meet Haruki

10 years old

"I don't like croissants... Just kidding, I LOVE croissants!"

Personality

Haruki is a ball of energy. He loves people, loves parties, and loves playing soccer. Both of his parents have achondroplasia, so they have a lot of experience with having been short-statured kids themselves! It's helped Haruki become more independent (sometimes, a little too independent!).

Mother

39 years old Has achondroplasia.

Father

42 years old Has achondroplasia.



Talking Points



Family

Both of Haruki's parents have achondroplasia, which means Haruki will be able to learn a lot from his parents' experiences growing up.



Specific Challenges: Getting Ready

Haruki's shorter arms and legs can make getting dressed and drying his hair more challenging. It doesn't mean he can't! Kids with achondroplasia will find their own ways to do things, even if they don't look familiar or they take more time.



Adaptations

Haruki's home has some custom adaptations to make it more comfortable for his family to go throughout their day. He also has a favorite step stool he's decorated like a skateboard.



Unique!

Haruki's parents aren't worried because they've been able to meet lots of different doctors with expertise to help support Haruki as he grows up living a healthy, active life.

Meet Emma

9 years old

"Do you like this dress? I made it myself! It has stripes!"

Personality

Emma has a big personality. She loves being the center of attention to show off all her favorite outfits and will talk your ear off about her two sisters: "They're both taller than me now, but that's only because they don't have achondroplasia."

Two Sisters

7 and 16 years old Do not have achondroplasia.

Father

45 years old Does not have achondroplasia.



Talking Points



Family

Emma is the middle sibling, and the only one in her family with achondroplasia. She has an older sister who was already growing fast when she was born—and now her younger sister is taller than she is, too.



Specific Challenges: Siblings without Achondroplasia

Every child is different, but it is not uncommon for children to begin feeling isolated as they see younger peers and siblings continue to grow auickly throughout childhood.



Adaptations

With so many people in the house, Emma's family tries to adapt what they can while Emma takes care of the rest. Her dad stresses the importance "asking when you need help," so Emma isn't shy about telling the people in her life what she needs.



Unique!

Growing up with two sisters, Emma's had to learn how to hold her own! Different experiences and people are what help shape us into who we are.



Using Bread to Discuss Achondroplasia (part 1)





DOUGH RISES; BONES GROW

- 1 Besides turning into Grandma's Famous Focaccia, dough can be used as a metaphor to help explain how people end up always being unique.
- lt can also be used to help explain the science behind bone growth, and what happens differently in the bones of somebody with achondroplasia.

BONES GROW; WE GROW

- More than 90% of the bones in our body start as something temporary called "cartilage" (the dough).
- As we grow (bake), our bones get longer when cartilage grows and turns into permanent bone (becomes bread).
- This is how our bones get longer and we increase in height (rise).





Using Bread to Discuss Achondroplasia (part 2)



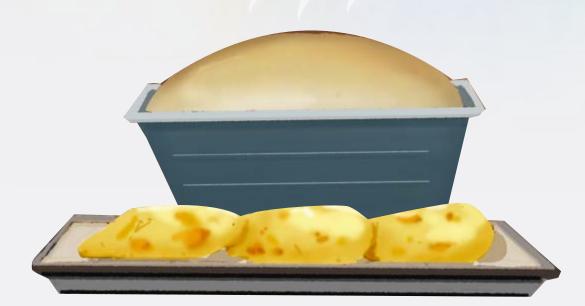


FGFR3 AND CNP: 2 INGREDIENTS

- 6 Like how water and flour are important ingredients for most types of bread, most of our bones have 2 main ingredients: FGFR3 and CNP to help control how these bones end up growing (rising).
- 7 In these bones, FGFR3 is a type of ingredient that slows bone growth (rise slowly), while CNP is an ingredient that makes bones keep growing (rise steadily).
- FGFR3 stands for Fibroblast Growth Factor Receptor 3
 CNP stands for C-Type Natriuretic Peptide

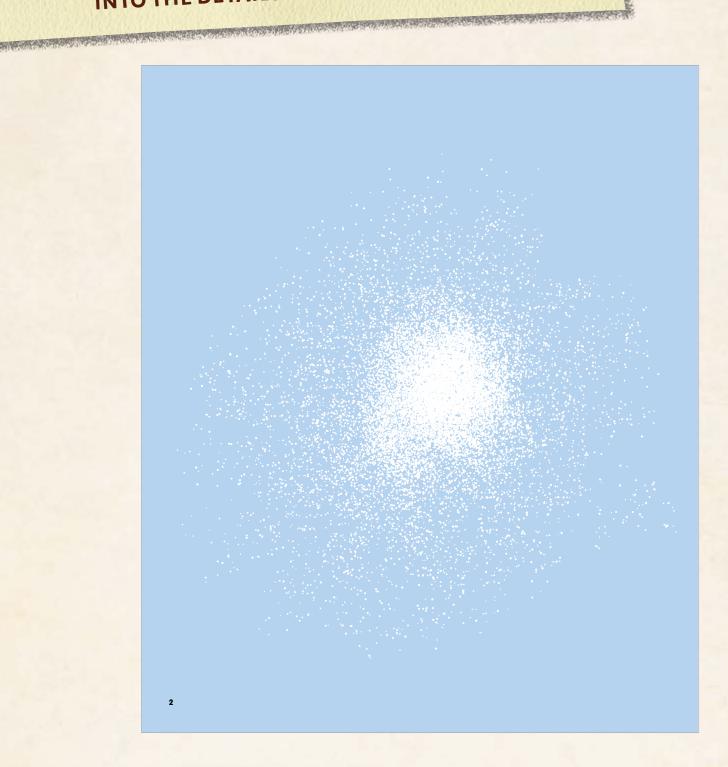
SAME INGREDIENTS; DIFFERENT AMOUNTS

- In the bones of someone who has achondroplasia, the balance of these ingredients is different. They have more FGFR3 than the CNP can keep up with.
- As a result, cartilage (dough) is told to stop turning into bone (rising) sooner than in bones with a closer balance of FGFR3 and CNP (ingredients).
- This is how achondroplasia can cause some kids' bones to grow differently than other kids. Same ingredients, just different amounts.





THE FOLLOWING IS A PAGE-BY-PAGE, DIVING INTO THE DETAILS WITHIN "RISING LOVE."

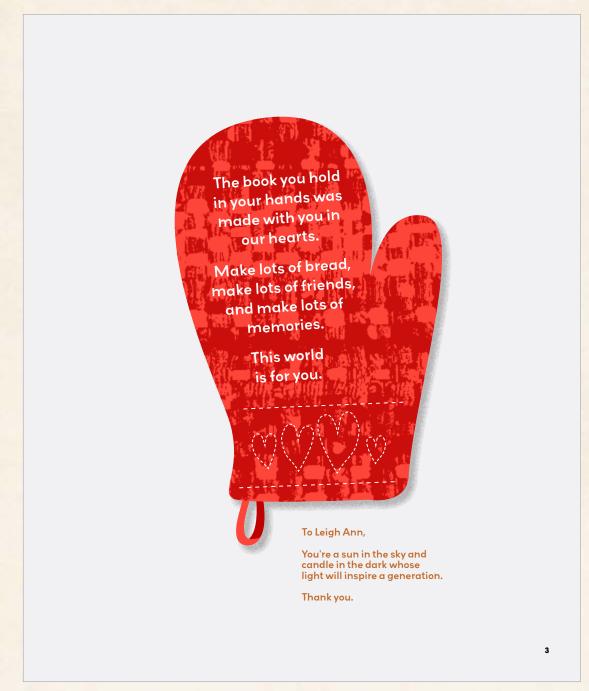


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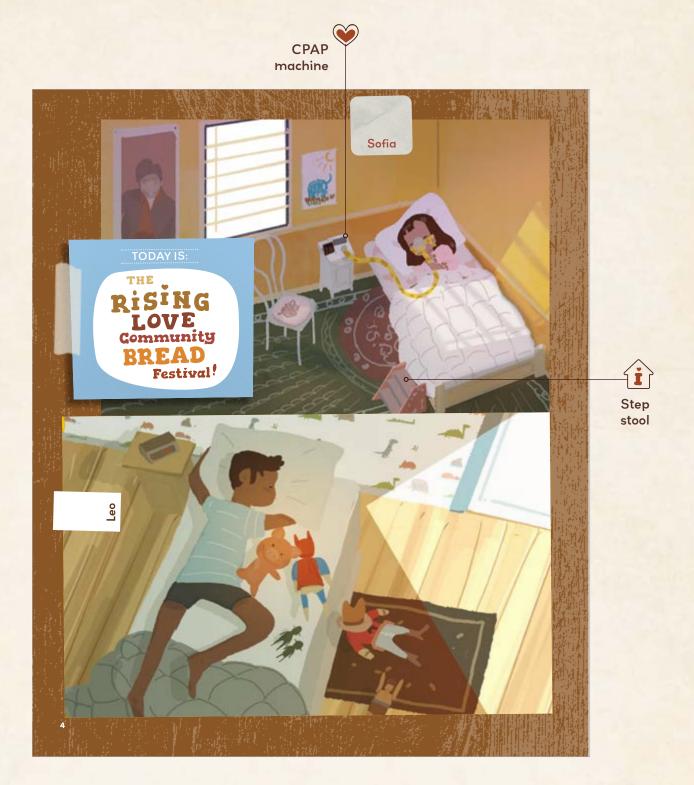


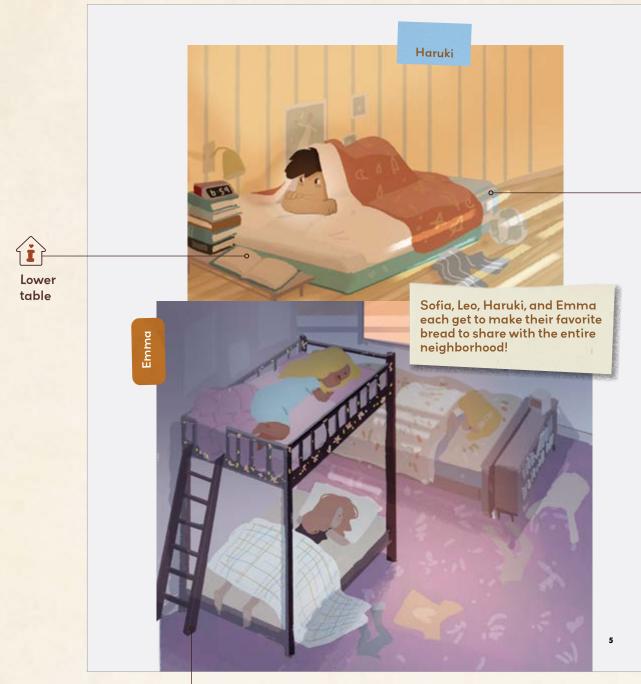






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A mattress

closer to the floor is common for kids, or even adults, with achondroplasia.

Sturdy ladders with wide enough steps are great for kids whose arms and legs are shorter.



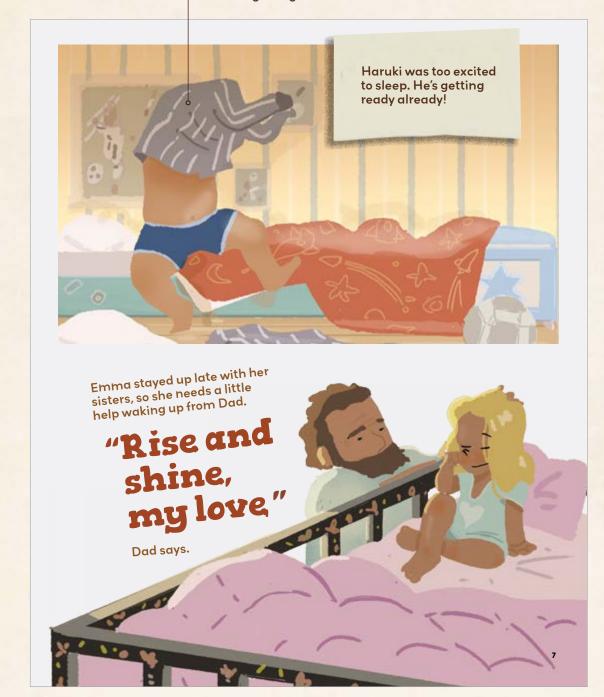
- A lowered bed and step stool make it easier for children with achondroplasia to get in and out of bed.



It is not uncommon for one sibling to have achondroplasia while the other does not.



Shorter limbs can sometimes cause difficulty with clothes when getting dressed.





There are lots of different types of stools, stairs, and other adaptations in the homes of people with achondroplasia.

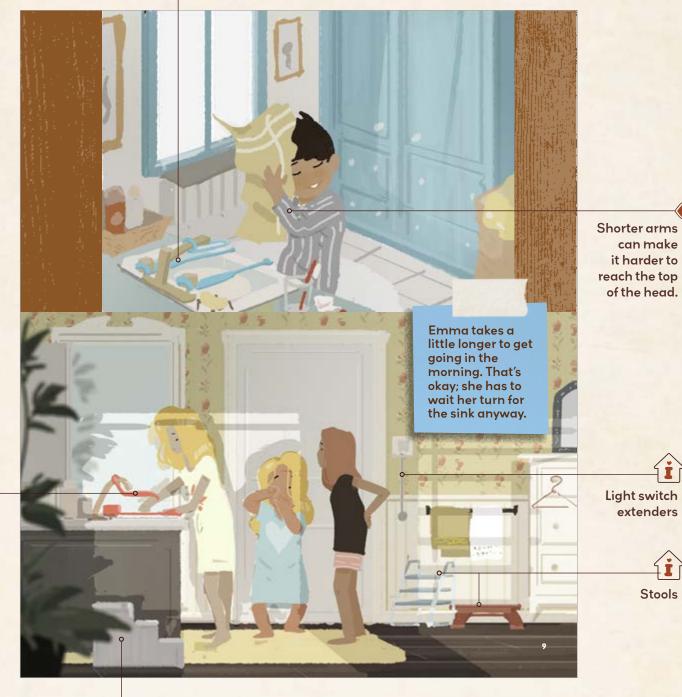




Sink extenders



There are adaptations to make reaching sink faucets easier for people with achondroplasia



it harder to

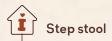


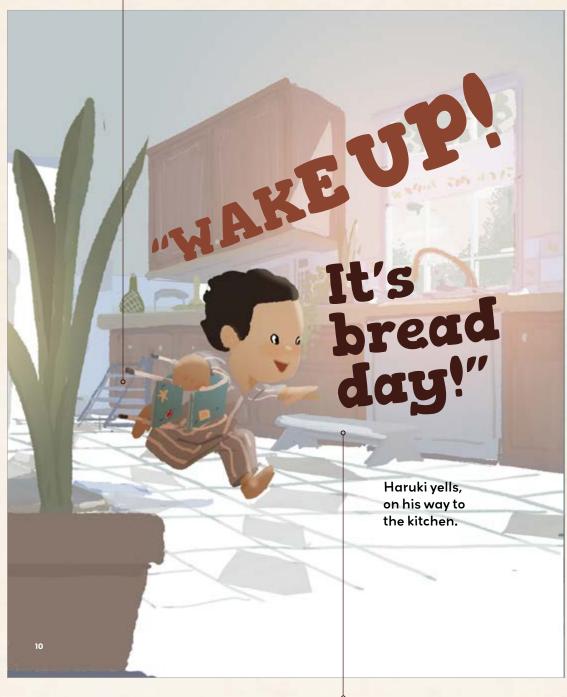
Sink extenders extenders





Step stool









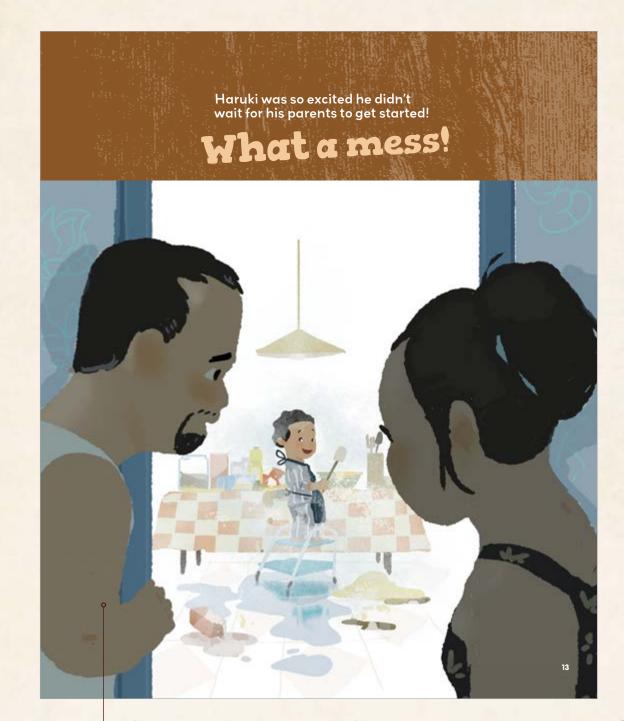
Light switch

extenders





Anyone can use a stool they're not just for people with achondroplasia!





There are families where the parents both have achondroplasia. That means some houses can be fully customized for people with a shorter stature.



Being comfortable asking for help can help any child build confidence in vocalizing what they might need assistance with.



Children with achondroplasia gradually develop their personal relationship to height.

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See Discussion Card:Bones Grow;
We Grow

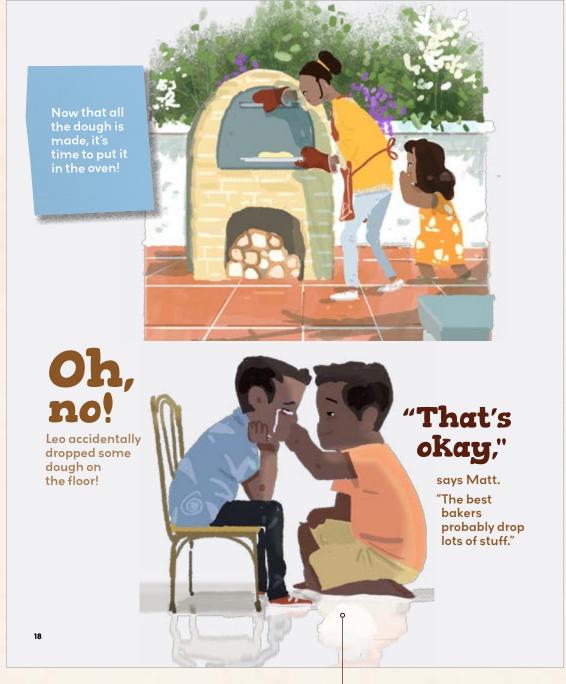
See Discussion Card: FGFR3 and CNP: 2 Ingredients



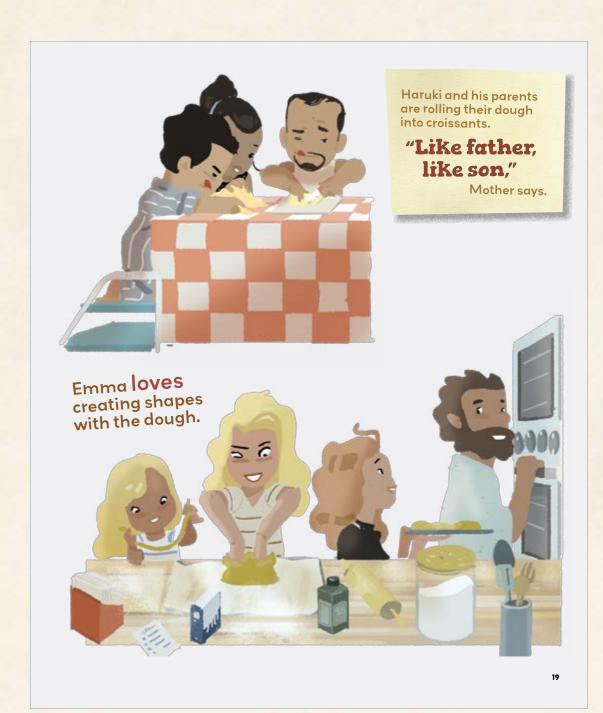
See Discussion Card:

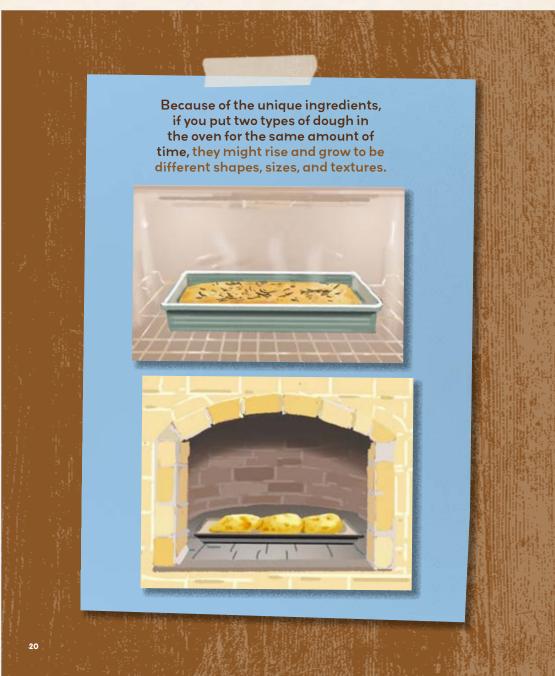
Dough Rises; Bones Grow

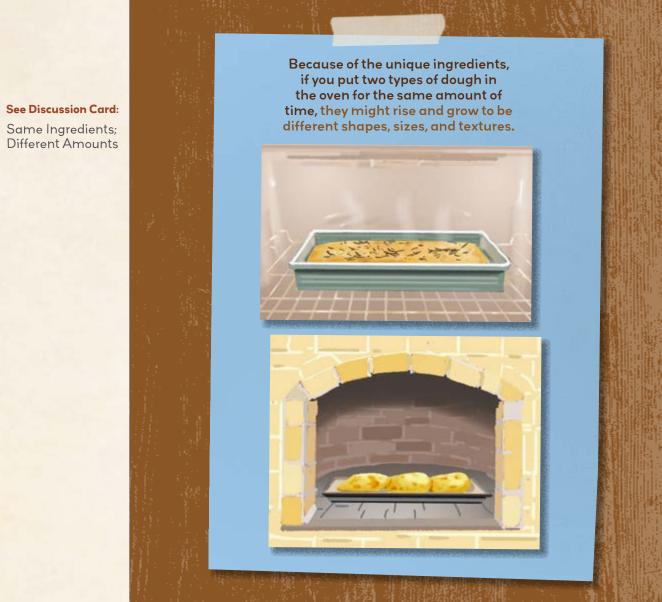


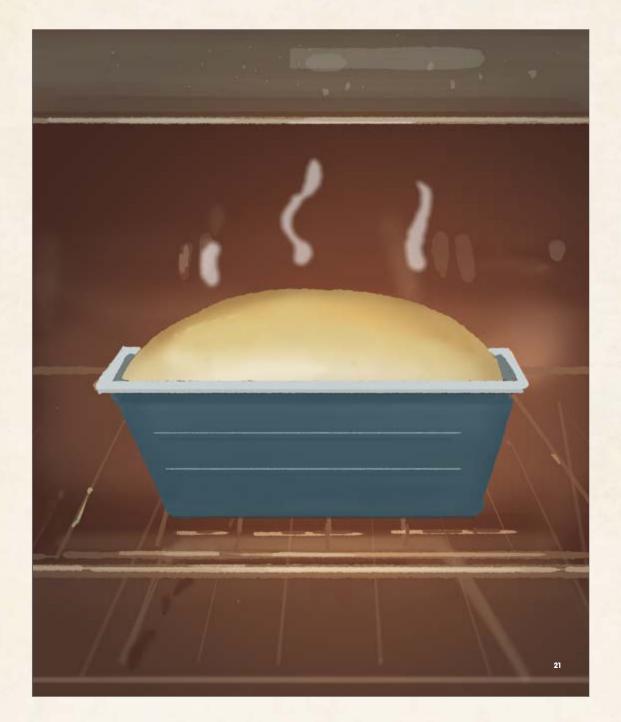


Anyone can be sad sometimes, but siblings and peers can be an important part of a healthy support network.











People with achondroplasia can drive with the use of pedal extenders, a higher seat or some

Every family has different style of adapting their car — some are even completely customized.

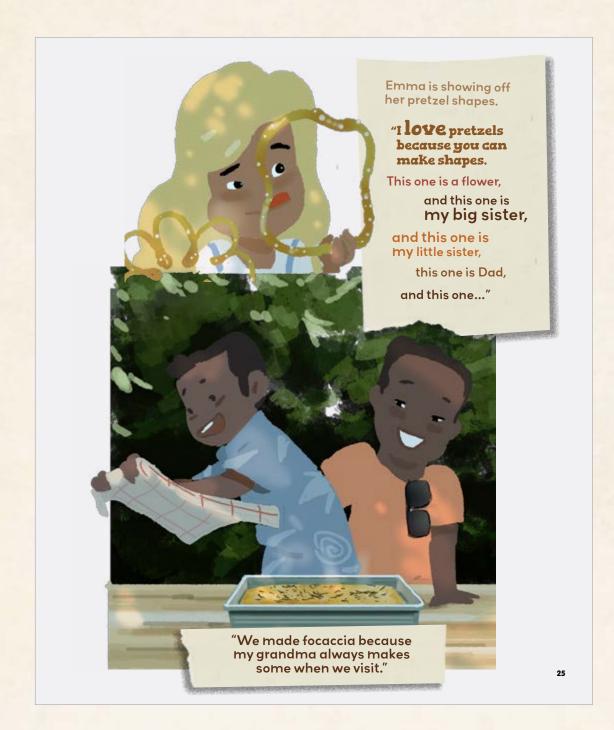
pillows, and back support.





Pillow for back support

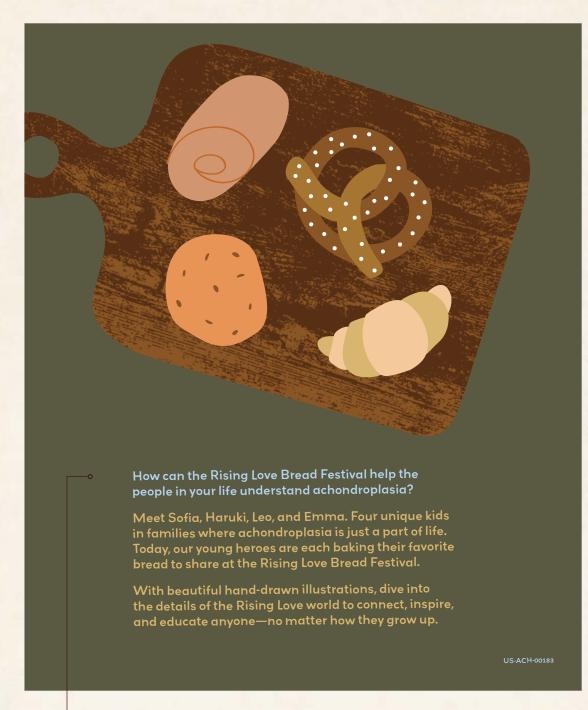














To learn more about achondroplasia, visit achondroplasia.com.



