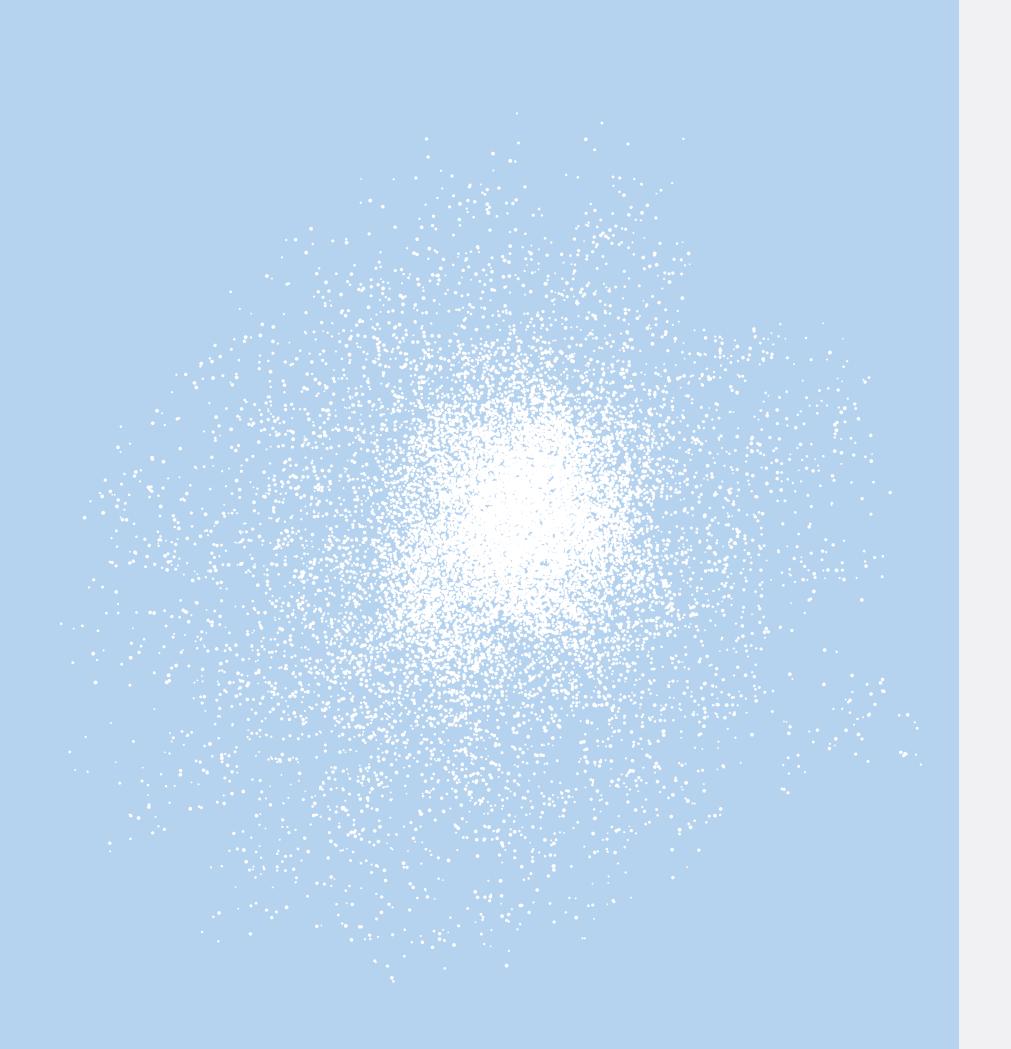




Bread, Community, and Achondroplasia

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Thank you.

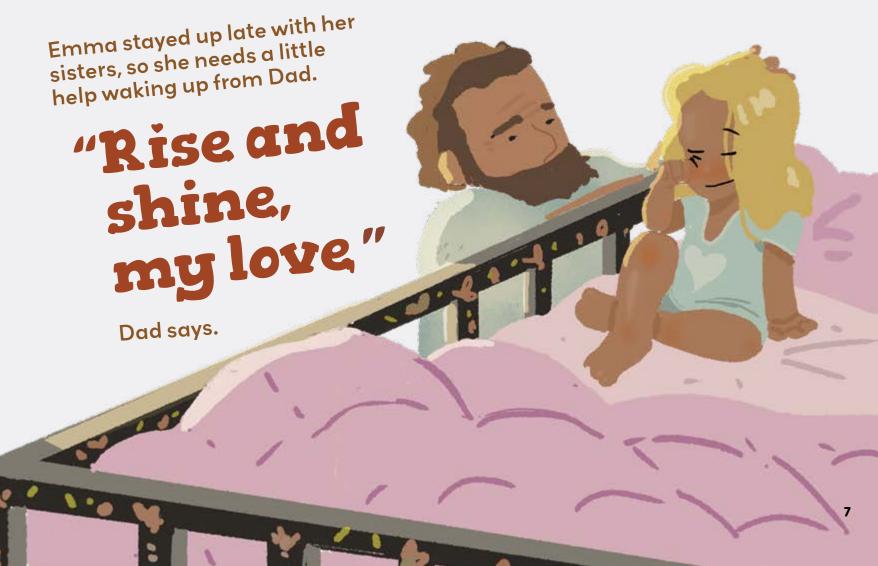
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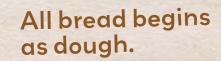












Dough then turns into bread after spending some time in the oven.



When making dough, recipes can use different amounts of different ingredients.



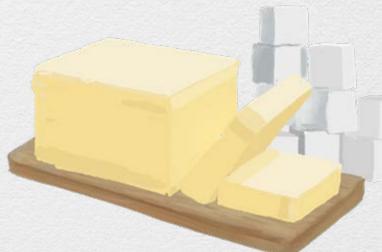
Most dough starts with flour and water...



Or maybe rosemary and garlic.



Some bread uses butter and sugar.



And others use baking soda and salt.



Even when dough has more or less of something, it can still be delicious. That's why there are so many unique types of bread!

Now that all the dough is made, it's time to put it in the oven!



Oh, no!

Leo accidentally dropped some dough on the floor!



"That's okay,"

says Matt.

"The best bakers probably drop lots of stuff."



Haruki and his parents are rolling their dough into croissants.

"Like father, like son,"

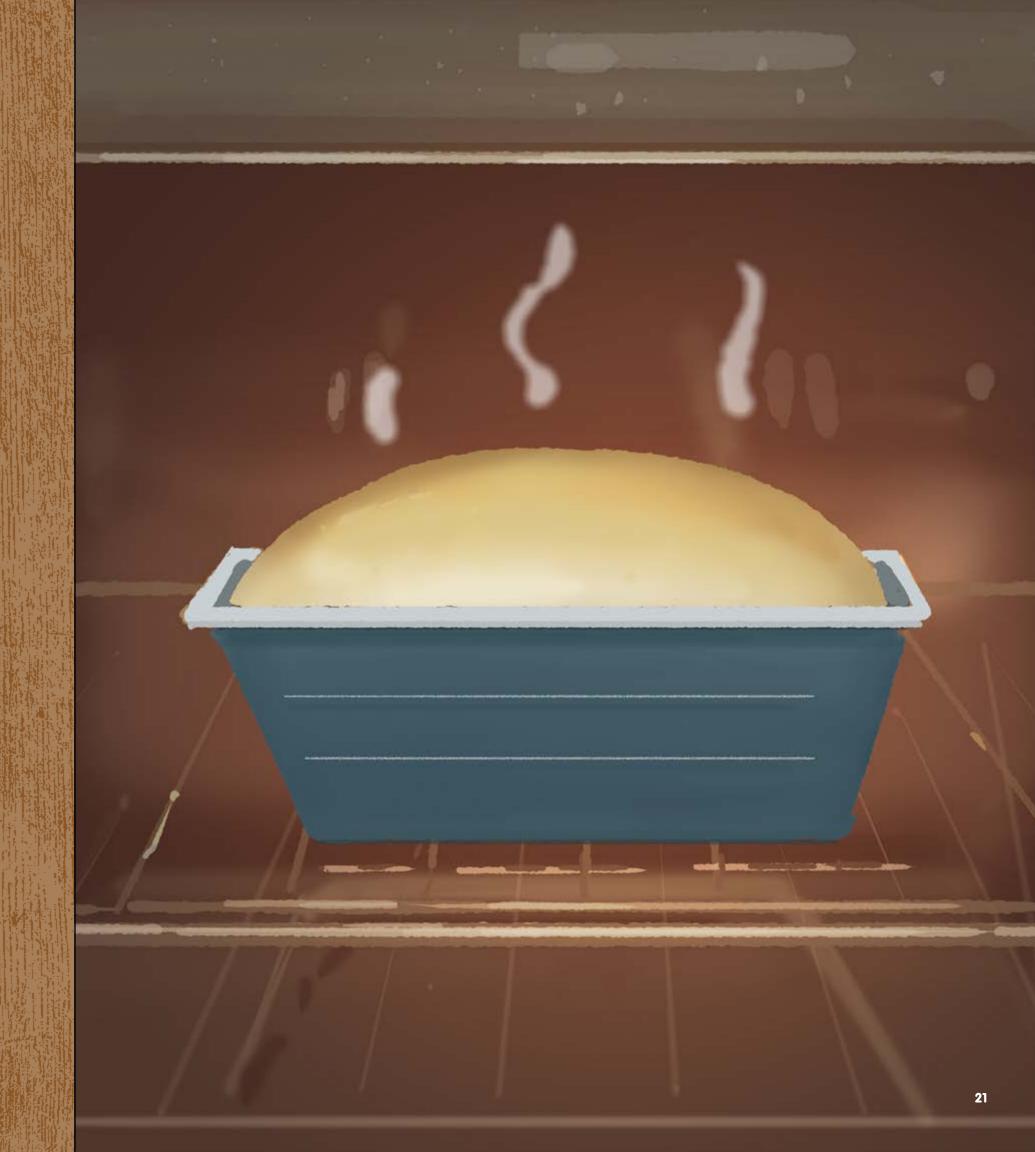
Mother says.



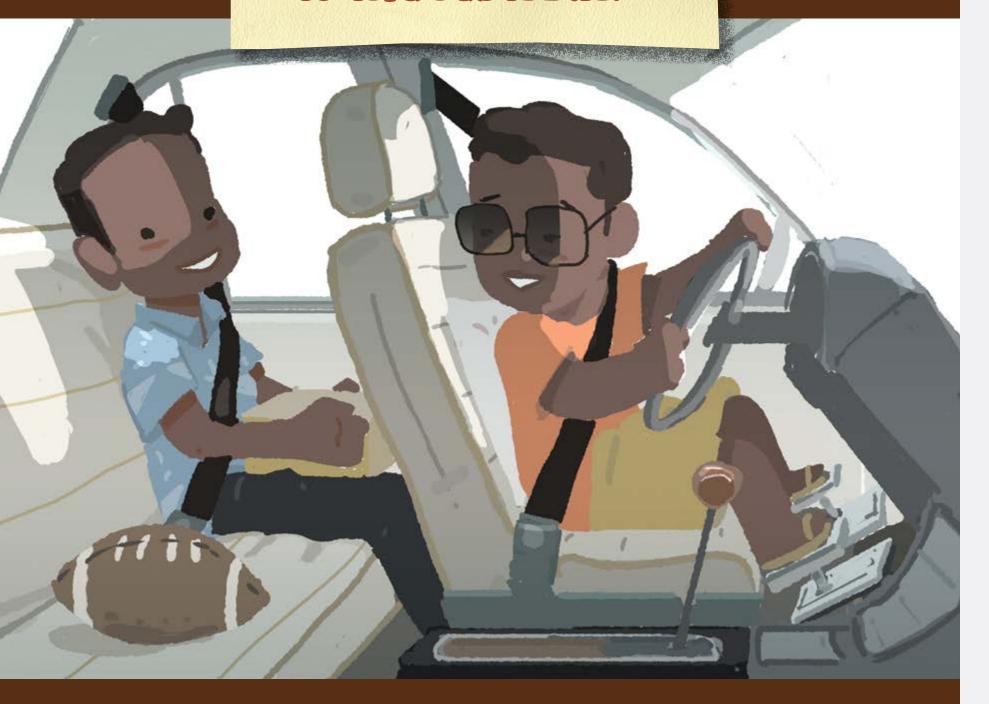
Because of the unique ingredients, if you put two types of dough in the oven for the same amount of time, they might rise and grow to be different shapes, sizes, and textures.







Now that the bread is made, it's time to go to the festival!



Leo can't wait to learn how to drive like Matt.

"Good thing the park is just down the street!" jokes Leo.



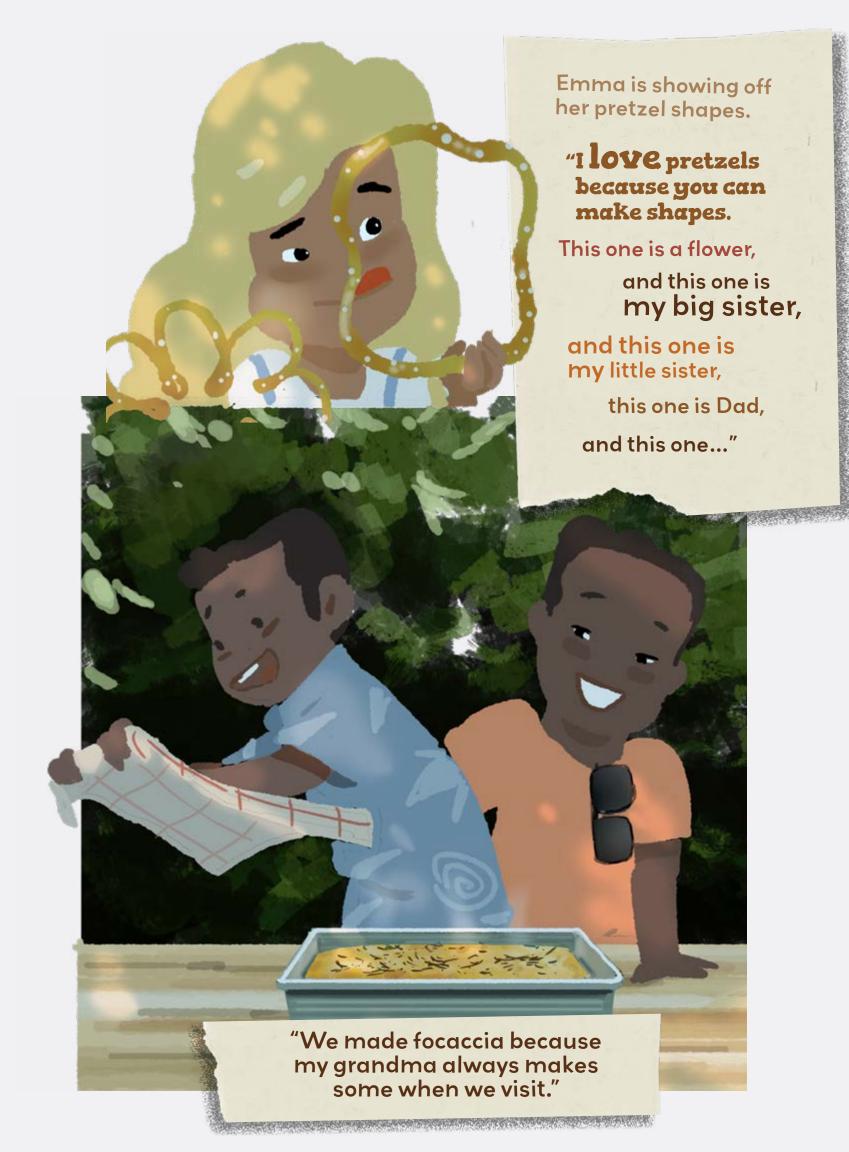




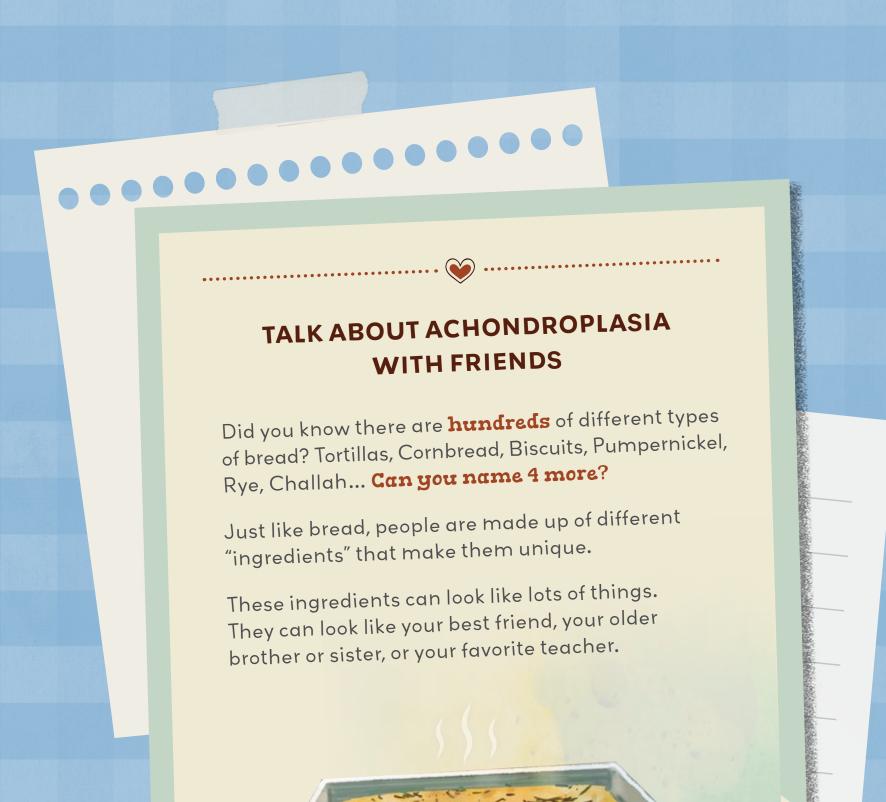
"croissants are the best

because I could eat an entire basket all by myself!"

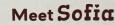
Haruki says through a mouthful of bread.











8 years old

# Meet the Families

### Meet Haruki

10 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

# "My 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**

16 years old Has achondroplasia.

#### Father

40 years old Does not have achondroplasia.

#### Talking Points



#### **Family**

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

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!

### "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 quickly 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 of "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**

- 3 More than 90% of the bones in our body start as something temporary called "cartilage" (the dough).
- 4 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)





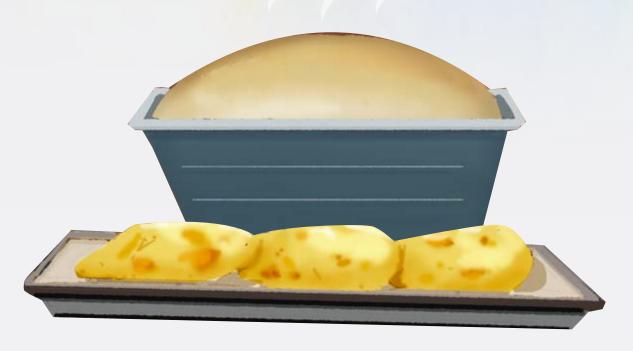
# FGFR3 AND CNP: 2 INGREDIENTS

- 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).
- 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).
- î

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.
- 9 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.





To see the full Reader's Companion for *Rising Love*, visit **achondroplasia.com**.



How can the Rising Love Bread Festival help the people in your life understand achondroplasia?

Meet Sofia, Haruki, Leo, and Emma. Four unique kids in families where achondroplasia is just a part of life. Today, our young heroes are each baking their favorite bread to share at the Rising Love Bread Festival.

With beautiful hand-drawn illustrations, dive into the details of the Rising Love world to connect, inspire, and educate anyone—no matter how they grow up.