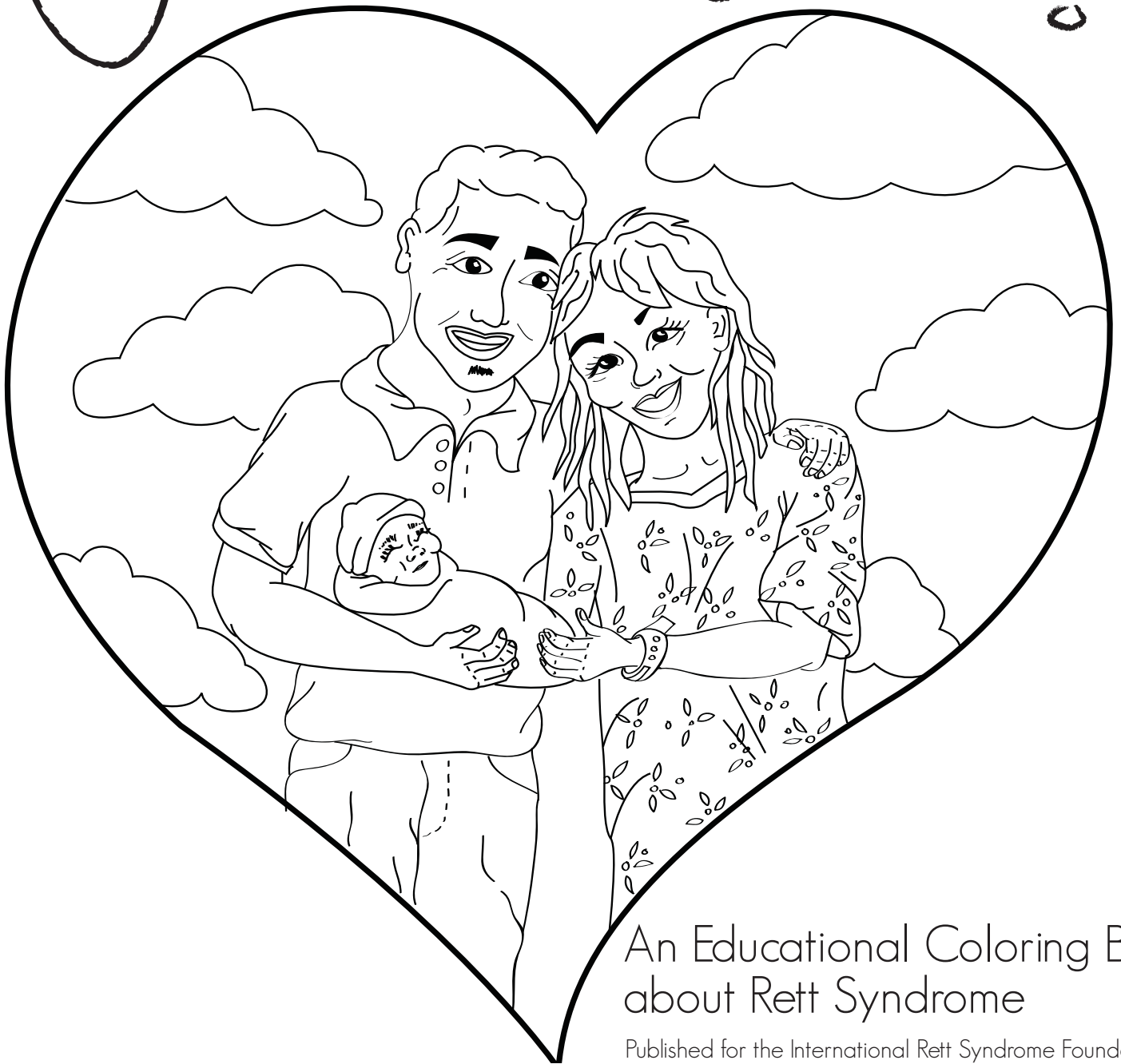


# Just Like Me!



An Educational Coloring Book  
about Rett Syndrome

Published for the International Rett Syndrome Foundation.  
All illustrations © Sarah Rose, 2010.

Three stylized sunflowers are drawn in the background of the page. They are simple line drawings with many petals and a central disk. One is at the top left, one is in the middle left, and one is at the bottom left.

## Goals for Coloring Book

To be an interactive tool, designed for educational use to better explain Rett syndrome to a young audience.

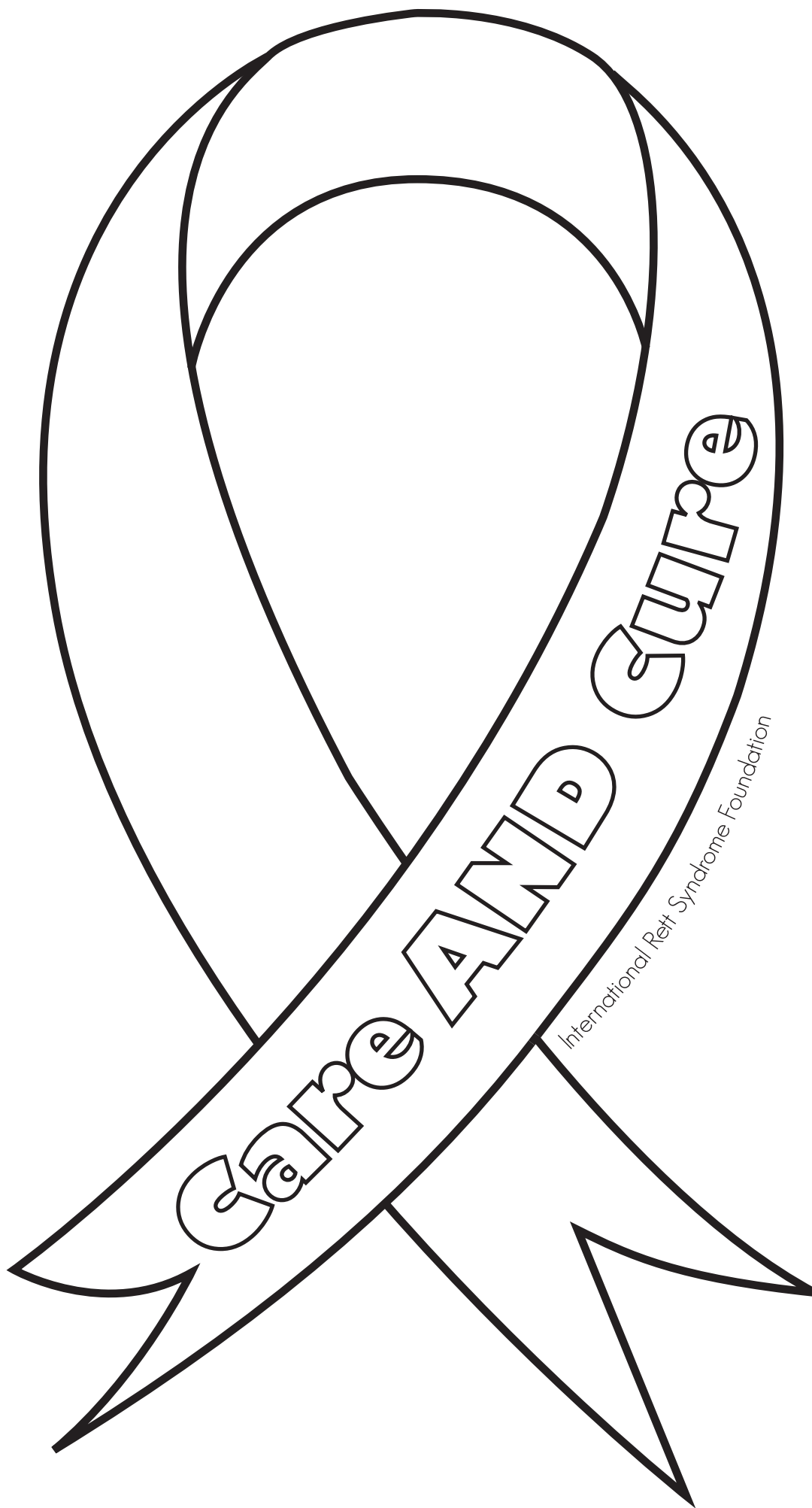
Please feel free to pass this coloring book on to friends, family members, teachers, students, etc. to allow a better understanding of Rett syndrome.

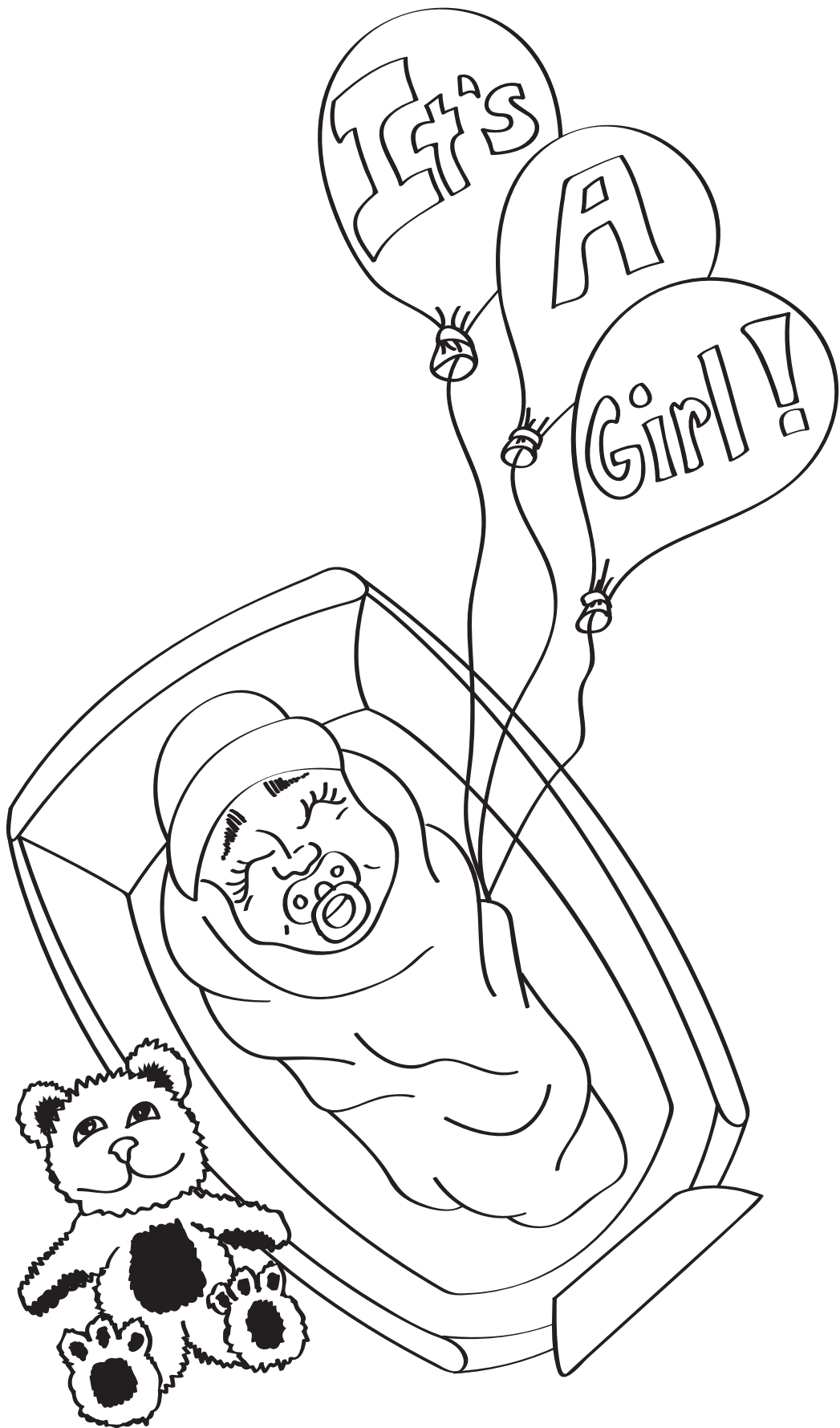
A kid-friendly description of Rett syndrome is located on page 13.

### Artist Biography

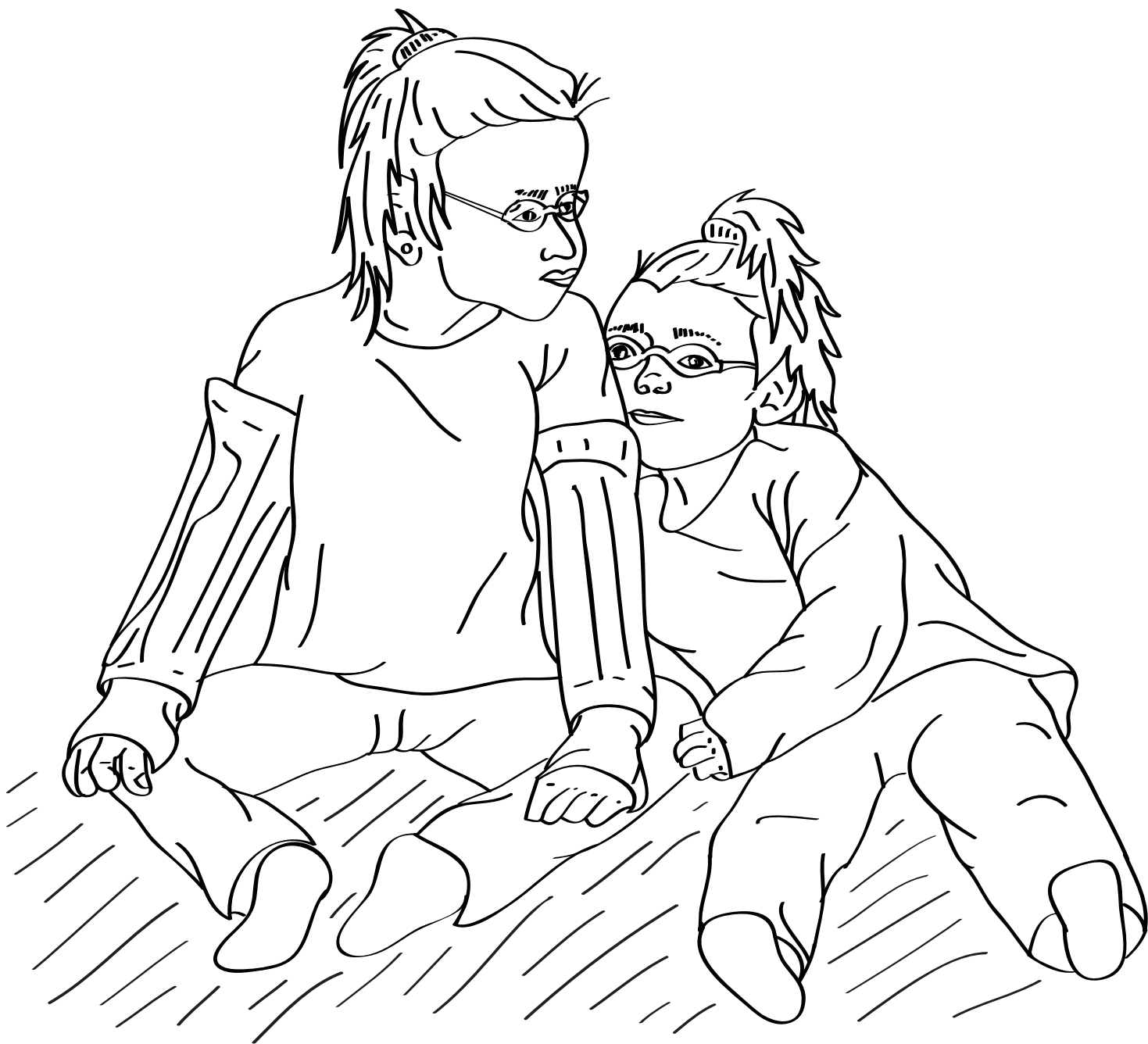
*SARAH ROSE* is a senior illustration major at Minneapolis College of Art and Design. Sarah has dreams of becoming a product and surface designer. After school, her goals include seeing her illustrations and designs applied onto anything from fabric to clothing, to stationery, to skateboards, etc. She is also very fond of volunteering and helping community organizations in her area. Most recently, she volunteered as an instructor and mentor for an Eco-Friendly Design Program (specifically for inner city girls, 12-18 years old.)

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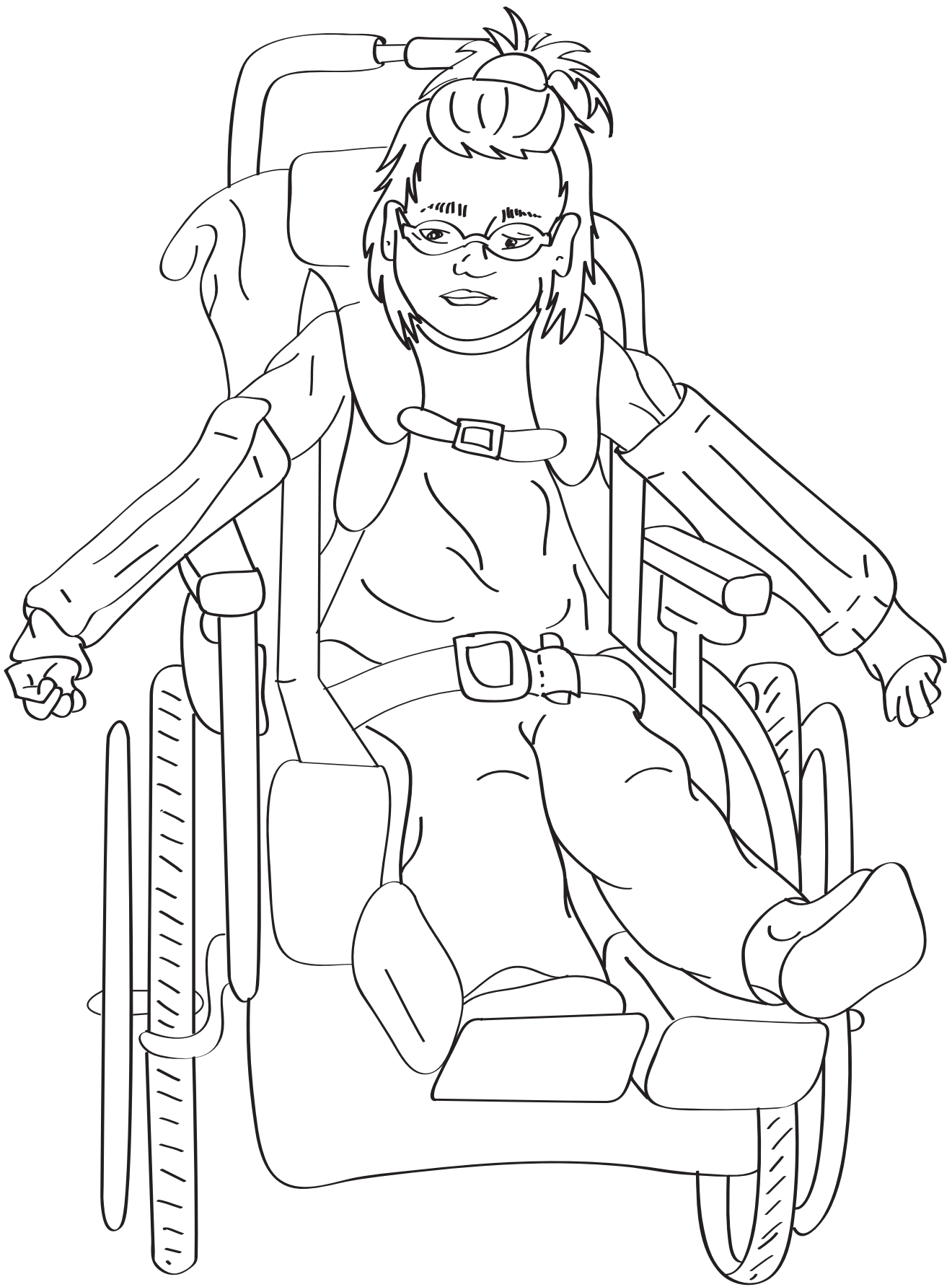




Rett syndrome is very rare and occurs in  
1 of every 10,000 female births.



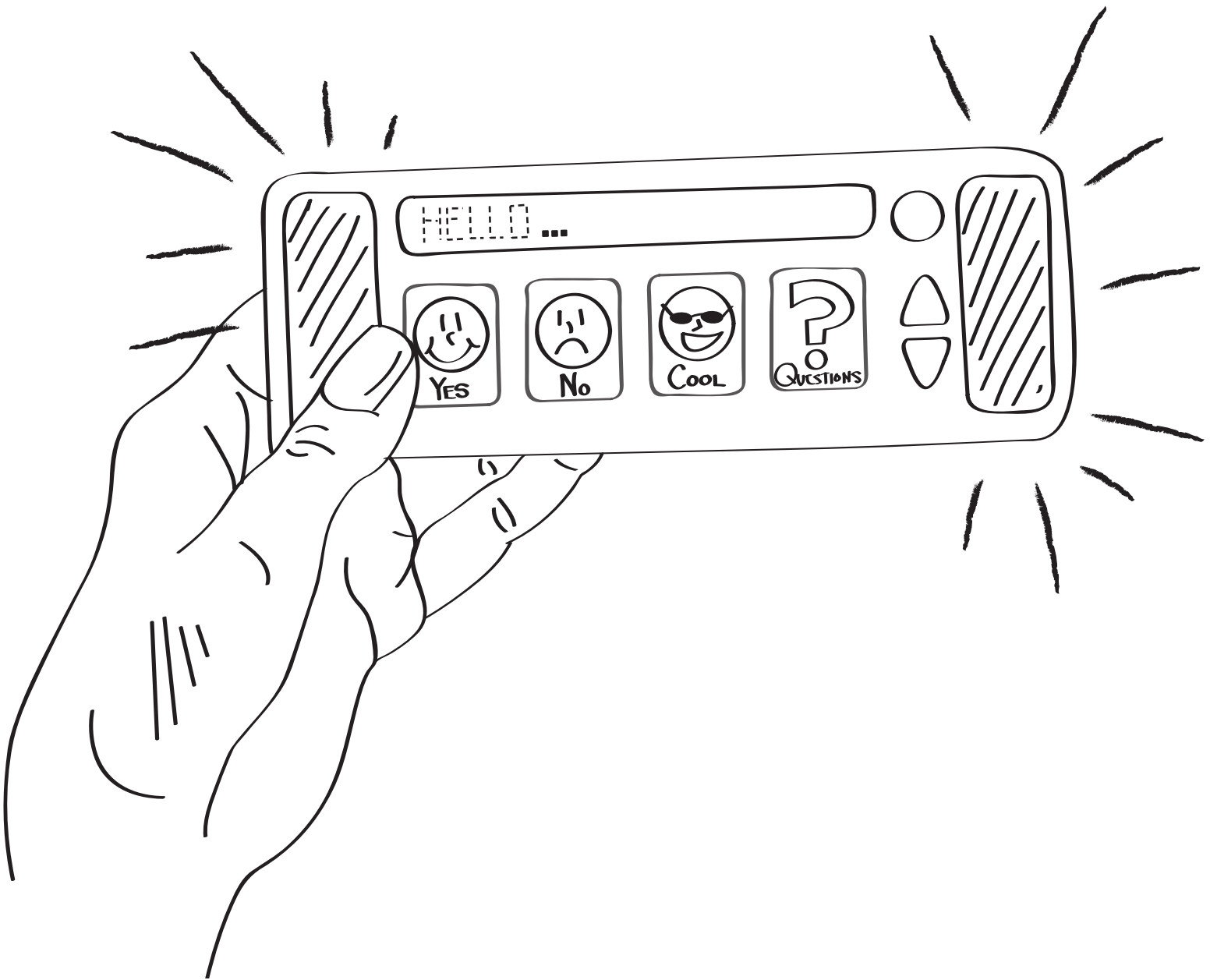
Rett syndrome is different in each girl.



They have trouble controlling their bodies.



Some walk, while others use wheelchairs.



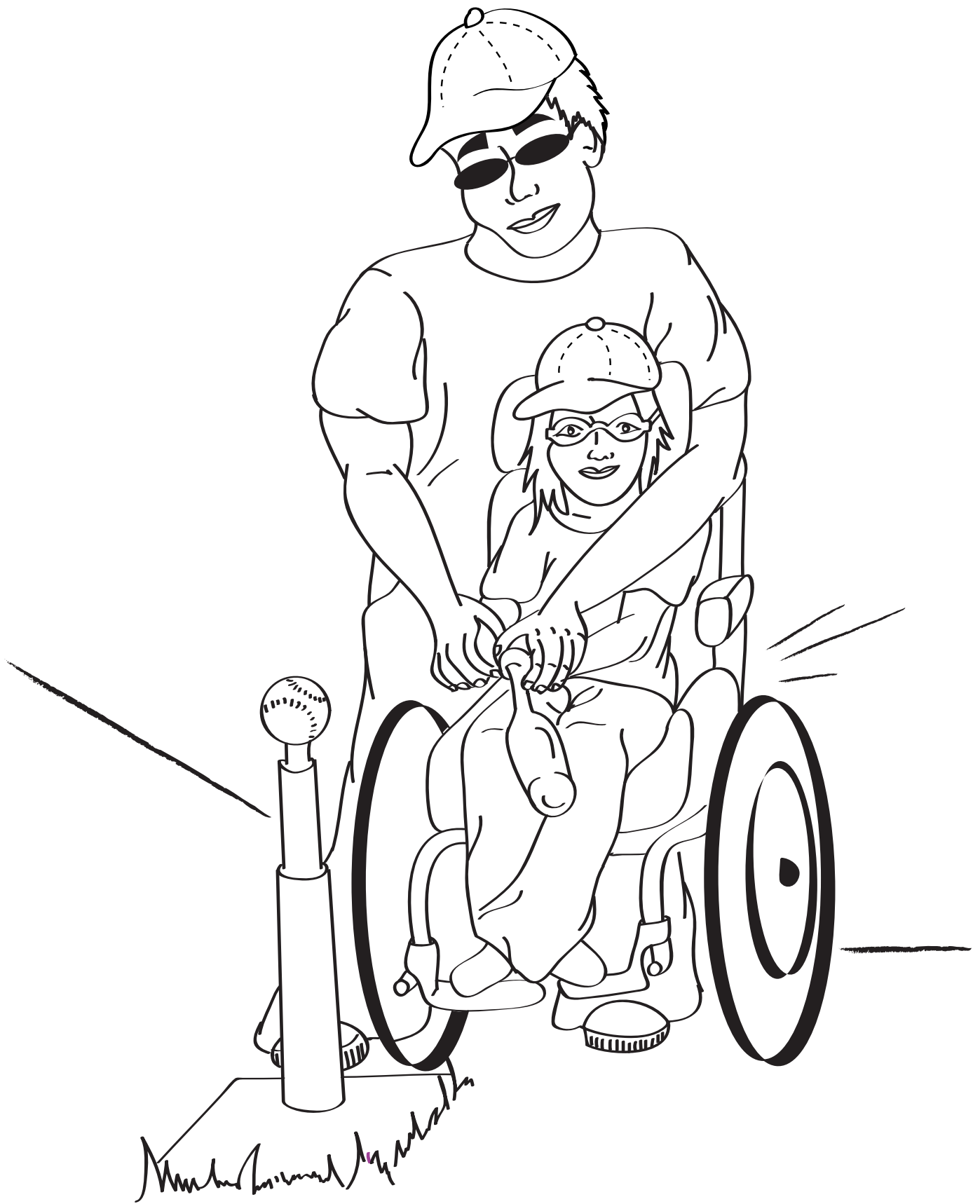
They cannot talk, but can use alternative means to communicate.



Girls with Rett syndrome are smart!  
They understand you.



They have feelings too...



and they love to play games!



They also have lots of friends-  
and would love to be friends with you!

## Rett Syndrome

Most people have never heard of Rett syndrome. But you might know a girl with Rett syndrome! She may live in your neighborhood or attend your school. You probably noticed right away that she makes special movements with her hands almost all the time. Do you wonder why? It is because she has a condition called Rett syndrome that affects her brain.

*Why is it called Rett Syndrome?*

Rett syndrome was named for Dr Andreas Rett, who first recognized the syndrome. A syndrome is a group of symptoms - when you put them all together they identify a special condition. Girls with Rett syndrome have the same symptoms.

*What are the symptoms of Rett Syndrome?*

Rett syndrome almost always happens in girls. When she is born, a girl with Rett syndrome seems to be healthy. She smiles, sits up and may begin to walk and talk. Within the next couple of years, though, she begins to lose skills and is no longer able to do what she once could.

*Here is a list of features or symptoms that must be present to call it Rett syndrome.*

Her head does not grow at the rate it should. She loses the ability to use her hands to pick up and hold things. She can no longer say words. She begins to make different hand movements such as clapping, "washing her hands" and putting her hands in her mouth. If she can walk, her legs are stiff and wide apart. She might walk on her toes. When she is upset or scared, her body trembles or shakes.

*She may also have other symptoms like the following:*

She may breathe differently, either holding her breath, called apnea, or huffing and puffing, called "hyperventilation". She may have seizures, which happen when her brain creates extra powerful jolts that make her behave or move differently. Seizures can be scary to watch, but they do not hurt her. She may have scoliosis, when her back curves so she is leaning to one side or leaning forward. She may grind her teeth.

continued on next page...

## *Rett Syndrome (continued...)*

Her feet are very small and cold. She is small for her age. She is almost always thin, even though she eats a lot. She may be irritable or not sleep as well as she should. She may have trouble chewing or swallowing. As she gets older, she may not be able to move and walk as well as she did when she was younger.

*What kind of problems does a girl with Rett syndrome have?*

She has a lot of problems that affect her in different ways. But the biggest problem is apraxia. Because of apraxia, her body cannot do what her brain tells it to - things like moving and talking. Just imagine how hard it would be to know what you want to do and not be able to do it, or to understand what someone says but not be able to show that you understand. It can be frustrating to have Rett syndrome.

*How much does she understand?*

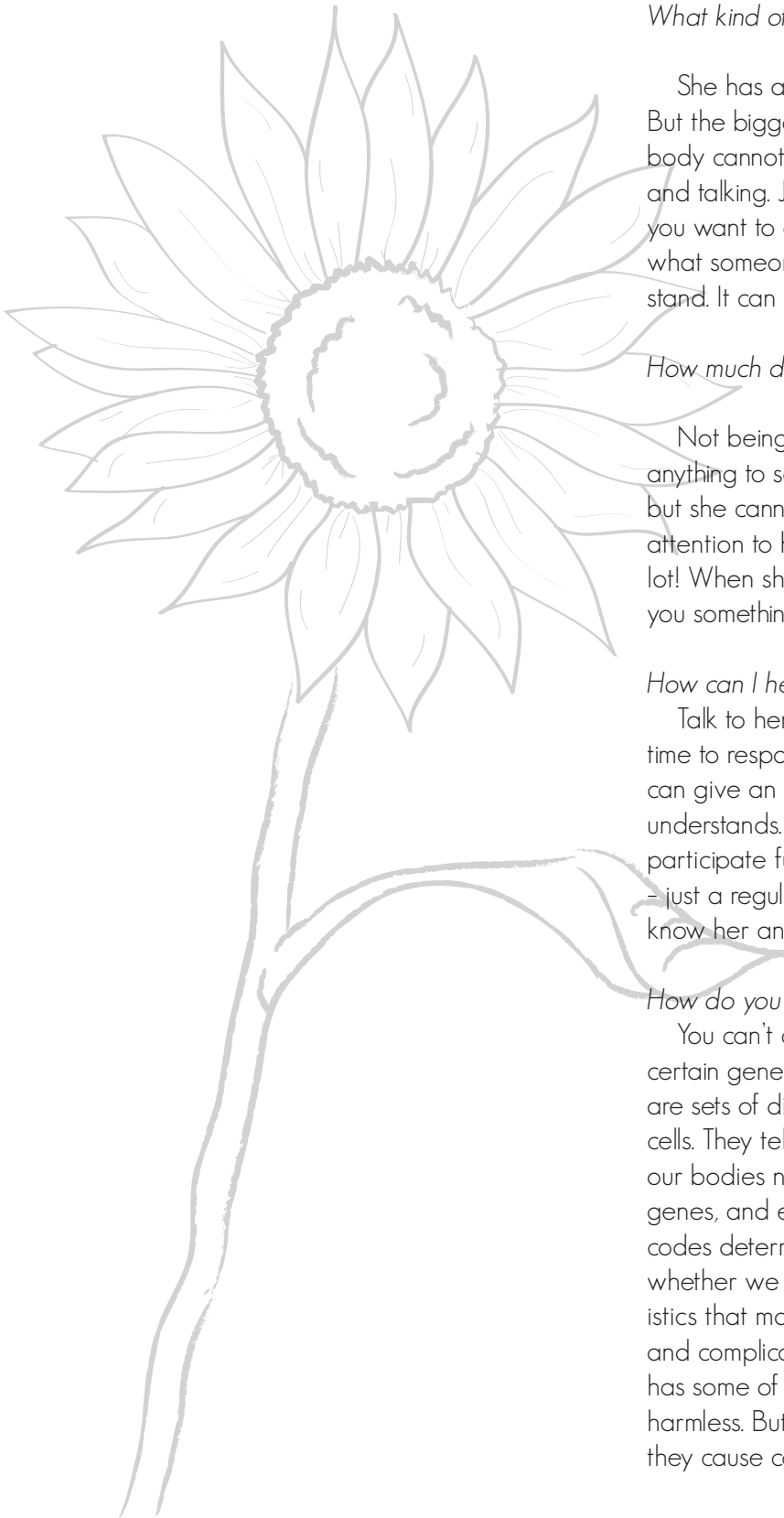
Not being able to talk doesn't mean she doesn't have anything to say! She probably understands everything you say, but she cannot speak or react the way you want her to. Pay attention to her body language and her eyes - they tell you a lot! When she is irritable or loud, she is probably trying to tell you something important in the only way she can. Be patient.

*How can I help her?*

Talk to her like you would someone else her age. Give her time to respond. Sometimes it takes several minutes before she can give an answer or make a movement to show you she understands. Include her in everyday activities even if she can't participate fully. She is really more like you than she is different - just a regular kid. And all kids have the same smile! Get to know her and you will see.

*How do you get Rett syndrome?*

You can't catch Rett syndrome! It is caused by a fault in a certain gene that a girl with Rett syndrome is born with. Genes are sets of directions that each of us carry in all of our body cells. They tell our body cells how to make the substances that our bodies need to function well. Each cell has thousands of genes, and each gene has thousands of pieces of code. These codes determine whether we will have blue or brown eyes or whether we will be short or tall and all of the other characteristics that make us all different. These chemical codes are long and complicated, so sometimes there are mistakes. Each of us has some of these mistakes, or mutations, in our body that are harmless. But sometimes, the directions get so mixed up that they cause conditions like Rett syndrome.



## Rett Syndrome (continued...)

*How come she seemed OK as a baby?*

The mixed-up gene is there even before she was born. It just takes some time for enough problems to develop for us to notice that something is wrong.

*How is Rett syndrome treated?*

A girl with Rett syndrome may need to take medicine to control seizures or to help her motor coordination or breathing. She also needs special therapies.

Physical therapy is used to help her keep flexible and able to move better and walk.

Occupational therapy helps her use her hands for everyday activities like eating and drinking, brushing her teeth, and even playing with toys or games.

Speech therapy does not teach her how to talk (apraxia makes that very difficult). It teaches her to use other ways to communicate.

Music therapy gives her another enjoyable way to communicate and to make choices.

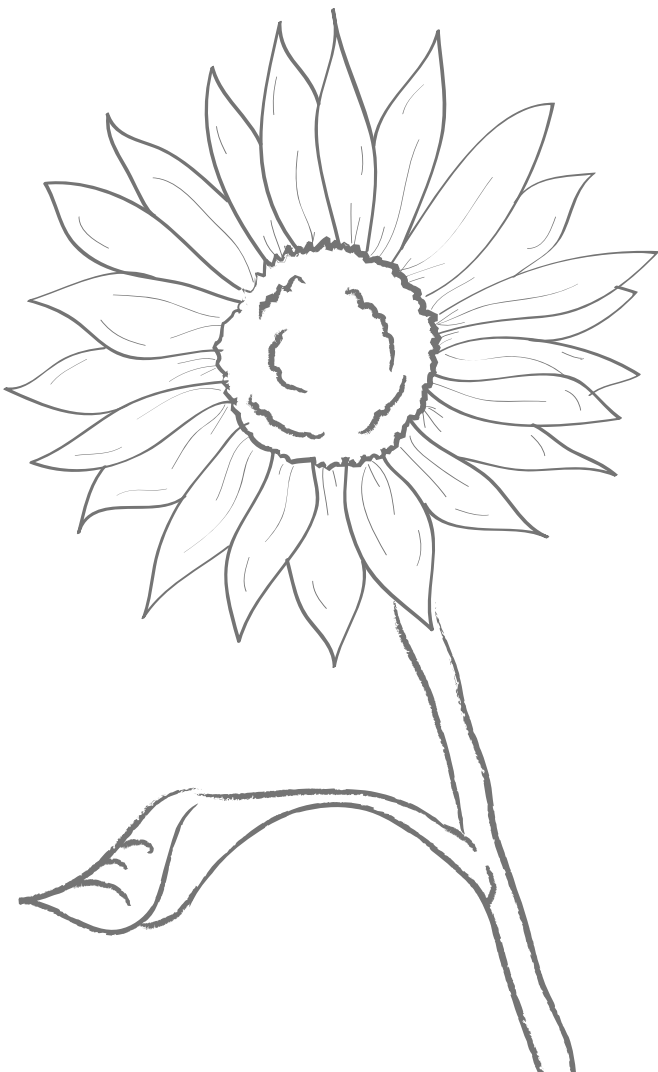
Through hydrotherapy, she is able to move more easily in warm water.

Many girls participate in horseback therapy, which helps strengthen muscles and improve balance.

Just like you and your friends, not all girls with Rett syndrome are exactly the same. Some girls go to special schools, while others attend their local neighborhood schools. They may learn in different ways, but they love to learn, just like you. They also love music, sports, animals, food and friendly people, just like you!

So now you know all about Rett syndrome!

\* For more information, please visit the International Rett Syndrome Foundation's website.  
<http://www.rettsyndrome.org/> for more information.



This book is dedicated to Emma and Katrina Johnson.  
A special thanks to the Johnson family for sharing their  
personal journey dealing with Rett Syndrome.