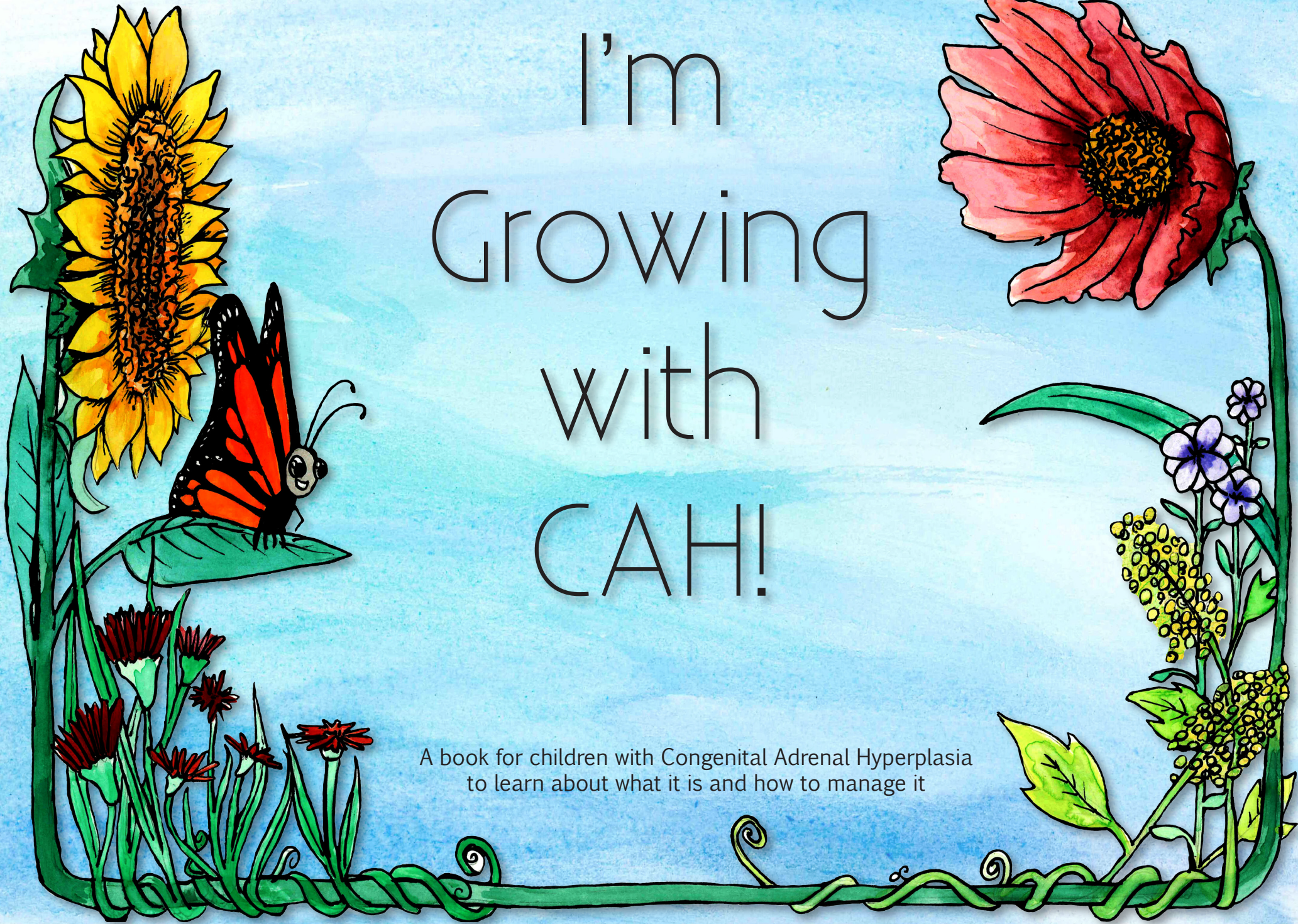


I'm Growing with CAH!

A book for children with Congenital Adrenal Hyperplasia
to learn about what it is and how to manage it





This book was developed by staff of the Minnesota Department of Health's Children and Youth with Special Health Needs section.

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This book belongs to:



This book is dedicated to all of the children living and growing with Congenital Adrenal Hyperplasia!

Also, a special 'thank you' to the families, caregivers, medical specialists, and other professionals who take such great care of these children.

In the U.S., about 4 million infants each year are tested by their state newborn screening program for Congenital Adrenal Hyperplasia (CAH), a life threatening form of adrenal insufficiency that affects 1 in 15,000 infants. Boys and girls with CAH lack an enzyme the adrenal gland needs to make cortisol and aldosterone, hormones that are essential for life.

Hi!

My name is Flutterby and
I like making friends.
Will you be my friend?

Some of my friends have
something called
Congenital Adrenal Hyperplasia, or CAH
— wait! You do, too?



Let's learn more about it together!

How do you know you have CAH?

Soon after you were born, the doctor took a few drops
of your blood and tested it.
That's how your family found out you have CAH.

Nobody tests baby
Caterpillars for
CAH...
I wonder why?



CAH stands for Congenital Adrenal Hyperplasia. What do those words mean?

Congenital means you were born with it. You did not get CAH because of something you did or said.

Adrenal means the part of your body called the adrenal glands.

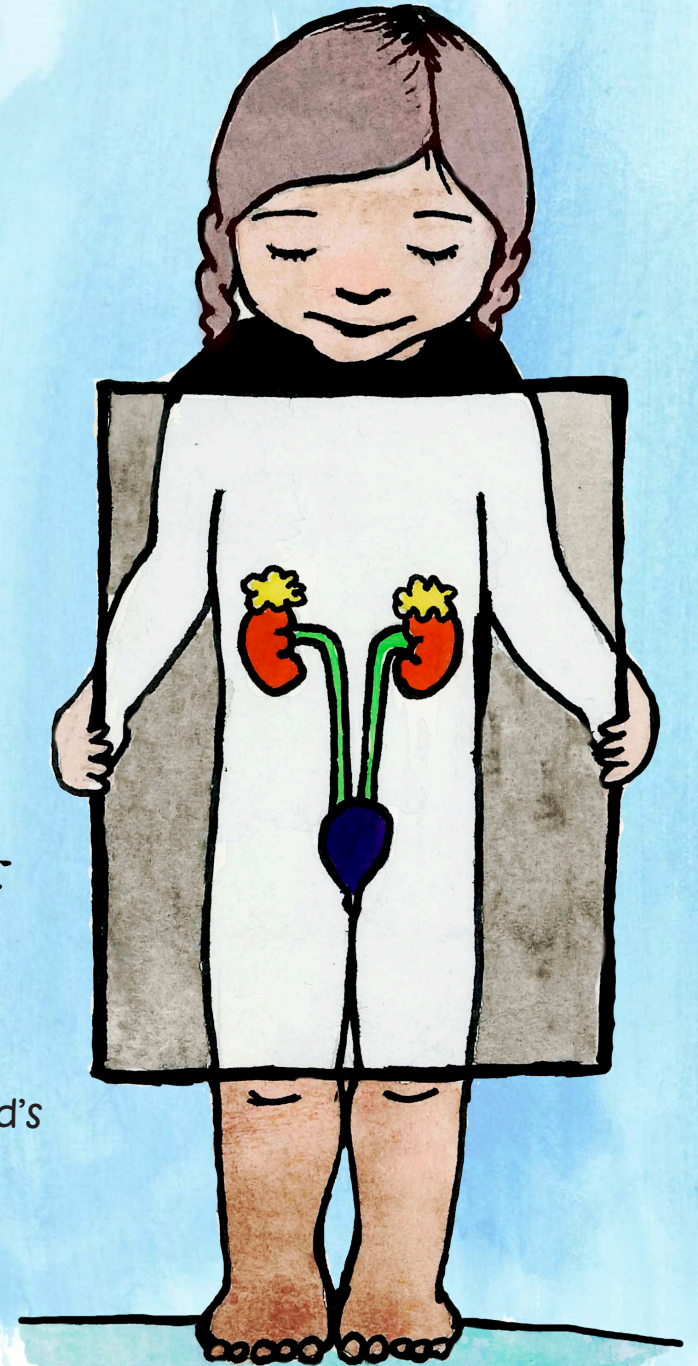
Hyperplasia is a big doctor word that some adults use for what is happening in your body.

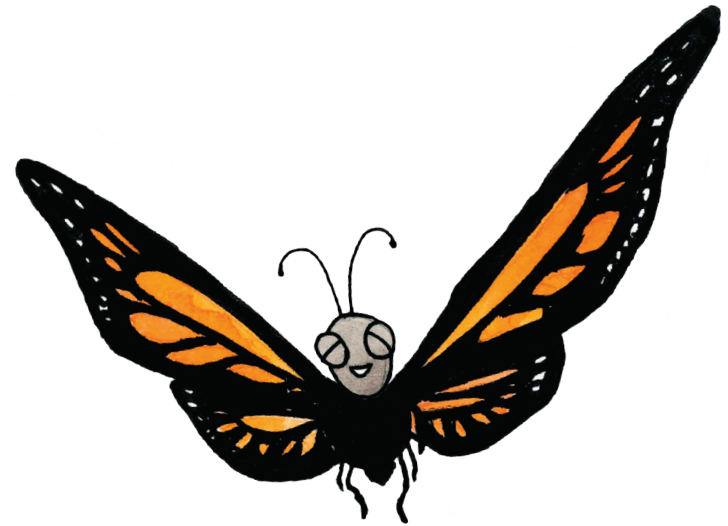


Can you point to your adrenal glands?



Can you see my friend's adrenal glands?
They are yellow.





CAH means your adrenal glands don't work the same way they do in other kids.

I'm so glad your family found out that you have CAH.

Now they know how to take care of you best!

I like flowers.
They have food for me to drink.
Sometimes I find flowers that need
more water than other flowers to
grow tall and strong. They stretch their
leaves up high and spread their roots
like toes to get the water they need.



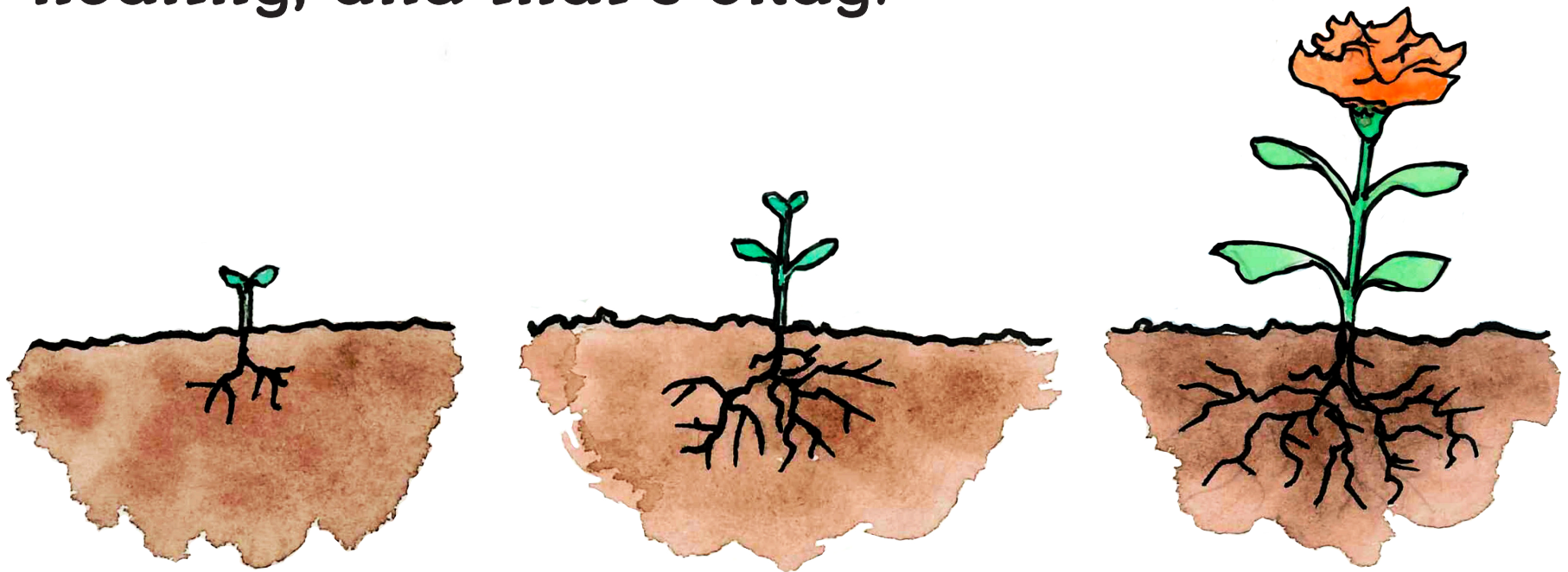
**Can you stretch out
like a flower?**

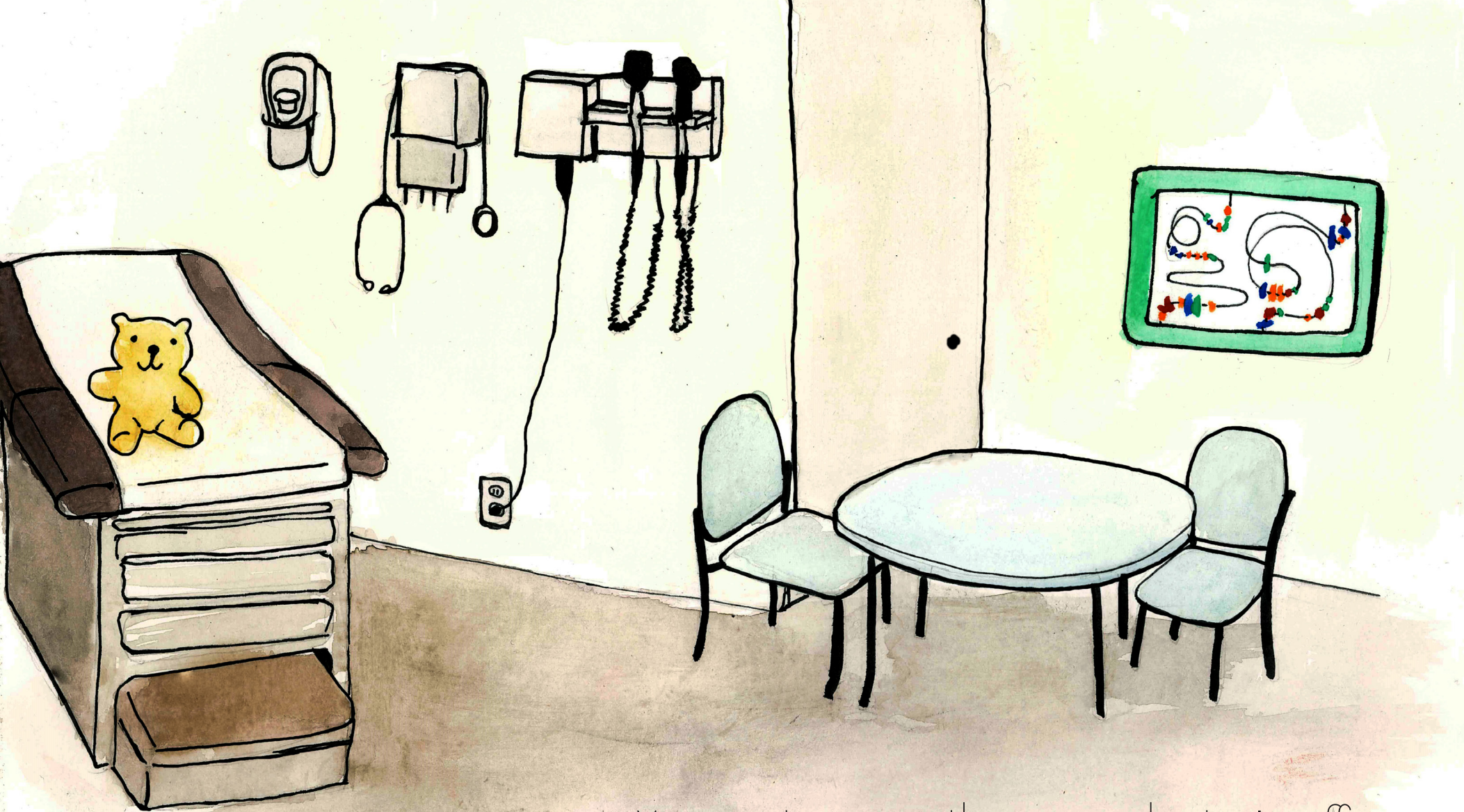
When flowers get the water they need, they can grow up healthy.

Kids are kind of like flowers.

Every flower needs water to grow, and some flowers need extra water.

Kids with CAH need different things to be healthy, and that's okay!





You go to more than one doctor's office.
You need to visit more often than some kids, too.



How many things can you name?
What does each thing do?

When you go to the doctor, they measure you.

You'll grow so much—you started as a baby and now you're bigger. Someday you'll be all grown up!



How tall are you
right now?



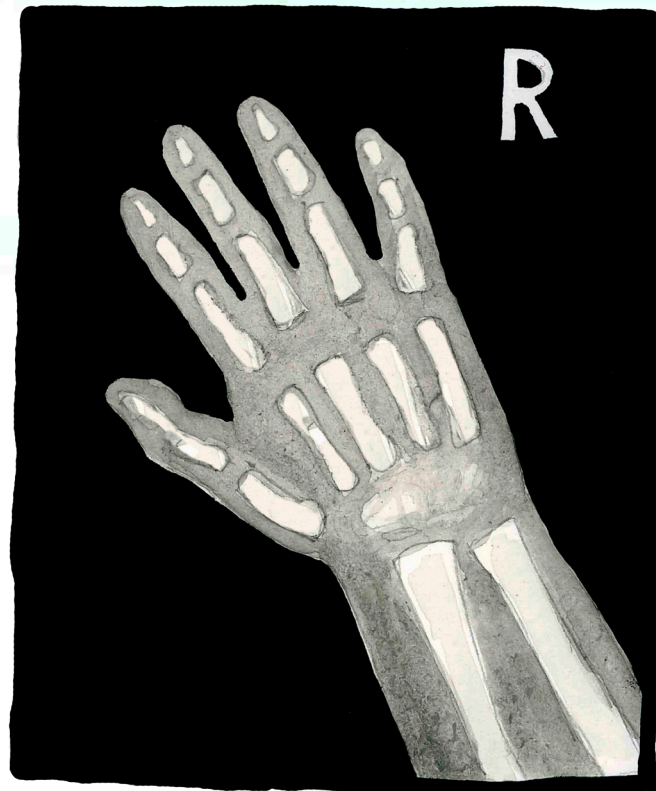
How much do
you weigh?

Another way doctors can check how much you are growing is to take a picture of your hand.

The machine taking the picture looks inside your hand at your bones.

This is called an X-ray.

It doesn't hurt.



Look at those bones!



Your doctor also needs to check your blood to make sure everything is working the right way. They might poke you in the arm. Sometimes pokes make people feel stormy, but it's OK to feel that way!

Remember how flowers need water to grow? Sometimes the water comes from a storm. Storms might feel scary, but the water is still important!

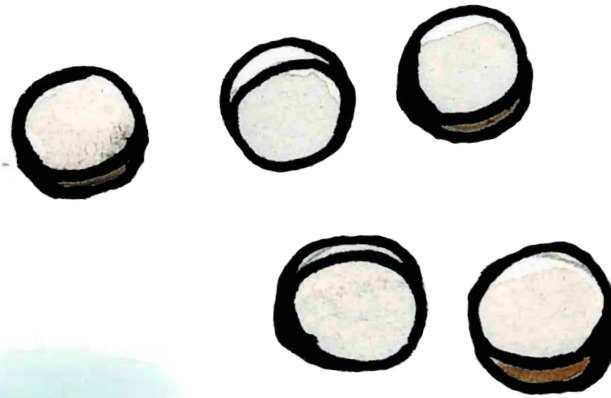
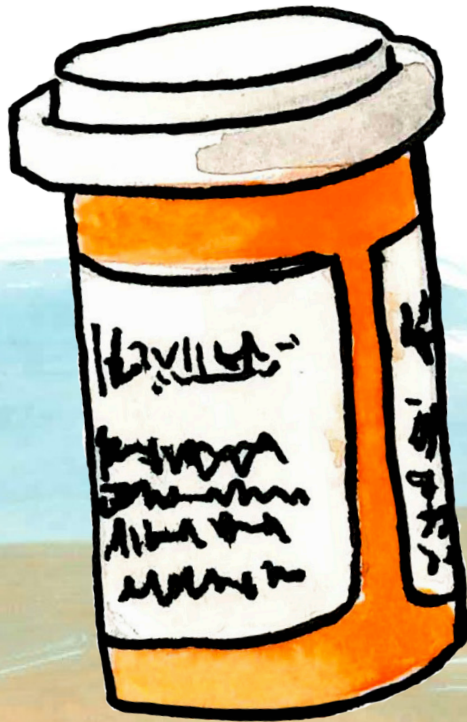
This is one of my friends. She just got a poke, but she hugged her teddy bear to stay calm.
There are lots of helpers to stay calm
- just ask if you need one!



What makes a poke easier for you?
What makes you feel less scared?

You take medicine for CAH.

This is because your adrenal glands don't make some things your body needs. You get these things from medicine instead!



Taking your medicine is important. How do you remember to take it every day?

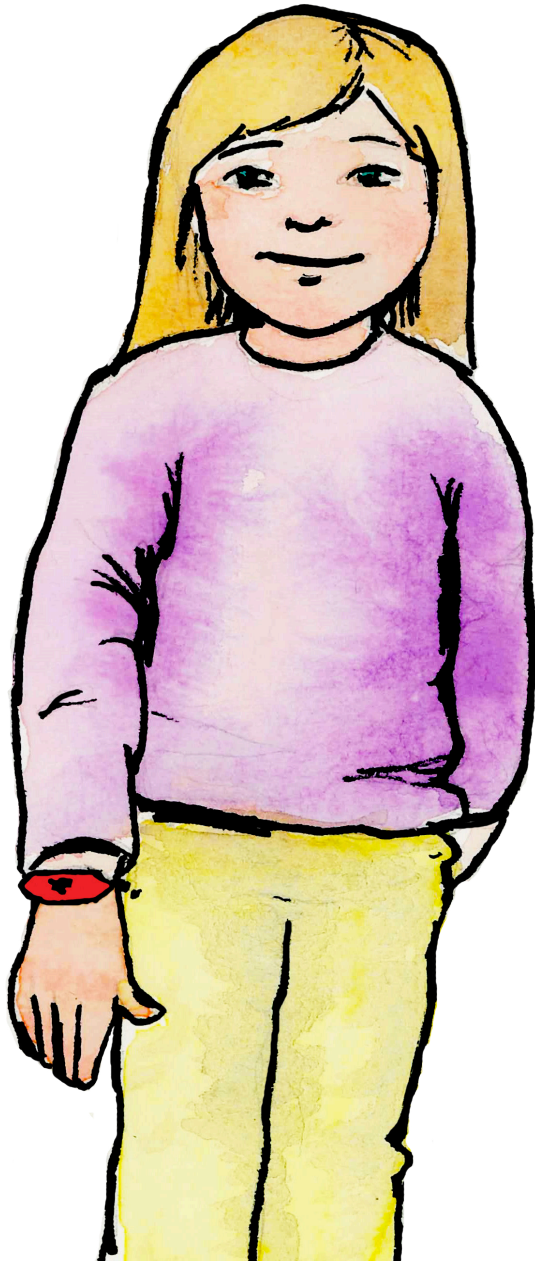


A lot of my friends wear a bracelet that can tell adults important things for emergencies.

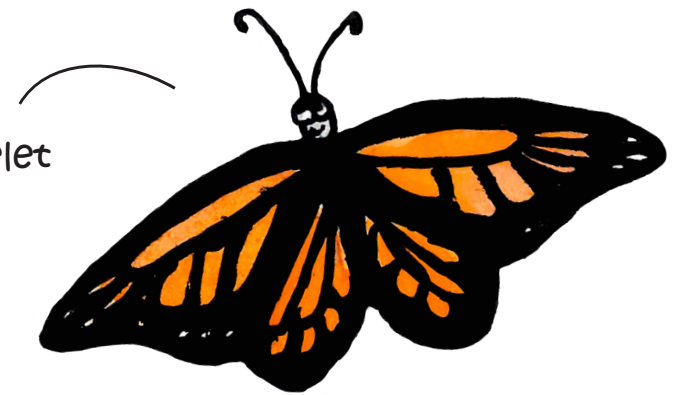
That's called a medic alert bracelet.

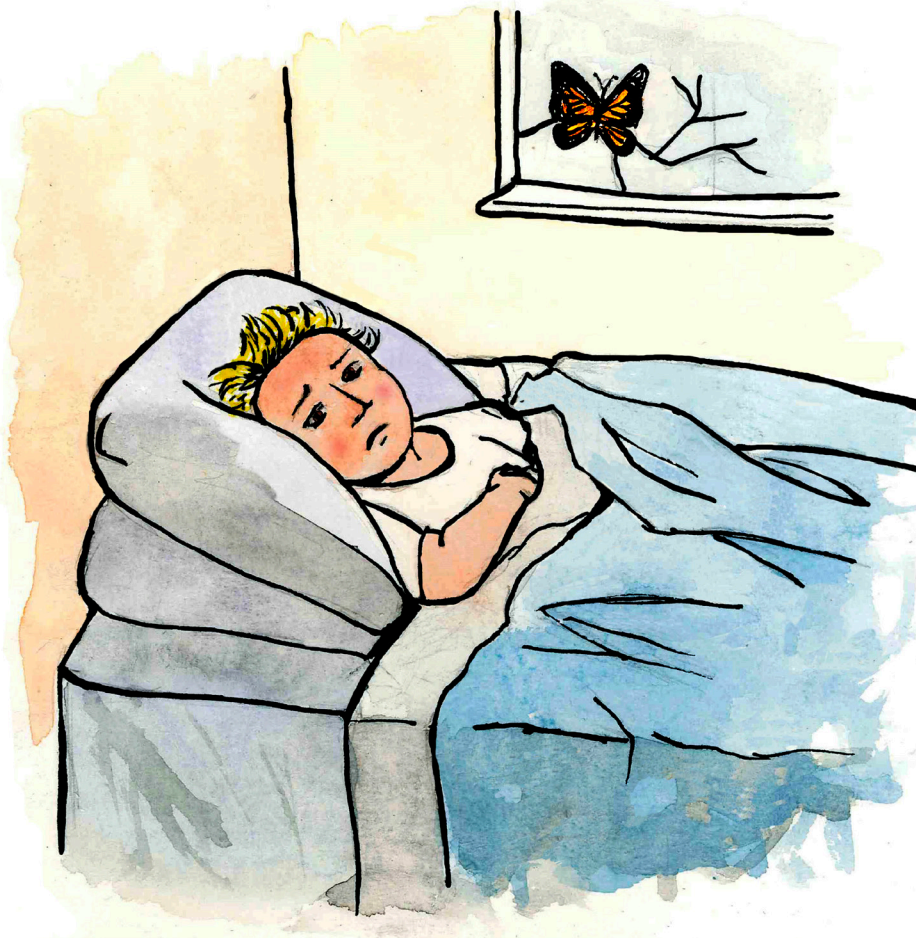
What does yours look like?

It's important to always wear your medic alert bracelet so everyone knows how to take care of you best.



My friend has a red bracelet
- her favorite color!
What color is yours?





The doctor also wants to know if your insides are hot or cold. What's that called?

Your temperature!

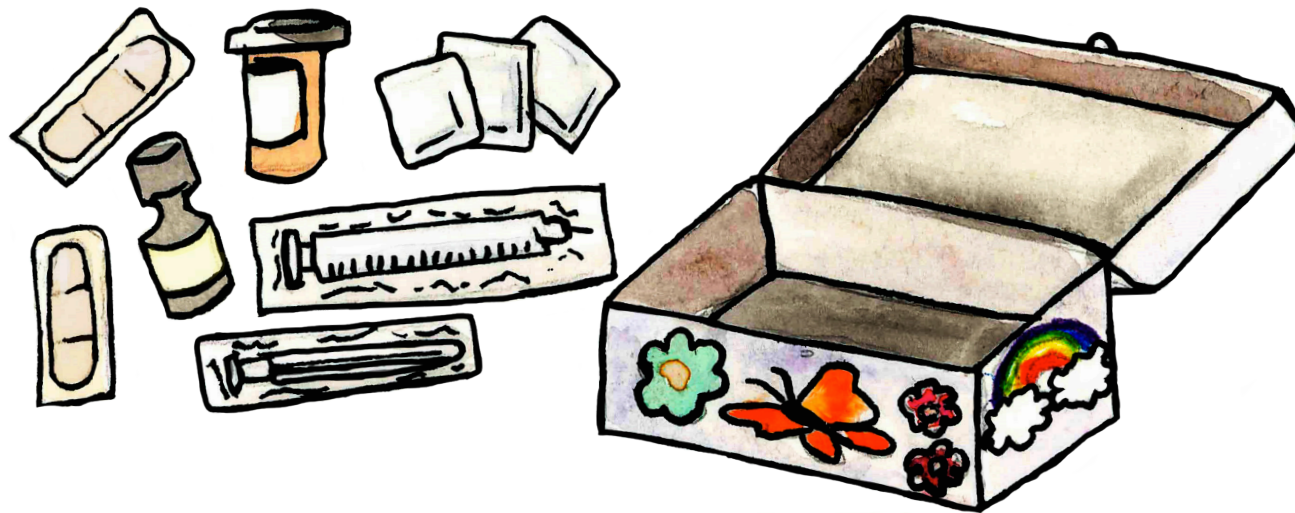
If your temperature gets too hot you might feel sick, so the doctor wants to make sure it is just right.

If that happens, you might have to take extra medicine or stay home. You might even visit a hospital. Your parents and doctors always do their best to help you! Always tell a grown-up if you feel sick.



Your family has a kit full of important things to help you in emergencies or other stormy times.

Other adults who take care of you might keep a kit with them too. Does your school have one? Who else has one?



This is what my friend's kit looks like!



What's in your emergency kit? What does everything do?



Medicine and doctors aren't the only things that help you grow.

Your family, friends, and teachers help too! You can talk about CAH with all these people if you want to.

All of my friends feel sad or scared about CAH sometimes.

If you are feeling sad, you can talk to someone about it.



Who do you talk to when you feel sad or mad or scared?

My friends with CAH are so great!
I watch them run and read and
paint and play.
They pick fun things to do, just
like other kids.

So can you!

I love watching kids grow. I'm
so happy you're getting what
you need to grow up strong,
just like my favorite flowers!



What do you
like to do?

Resources

The University of Minnesota Leo Fung Center for Congenital Adrenal Hyperplasia (CAH)

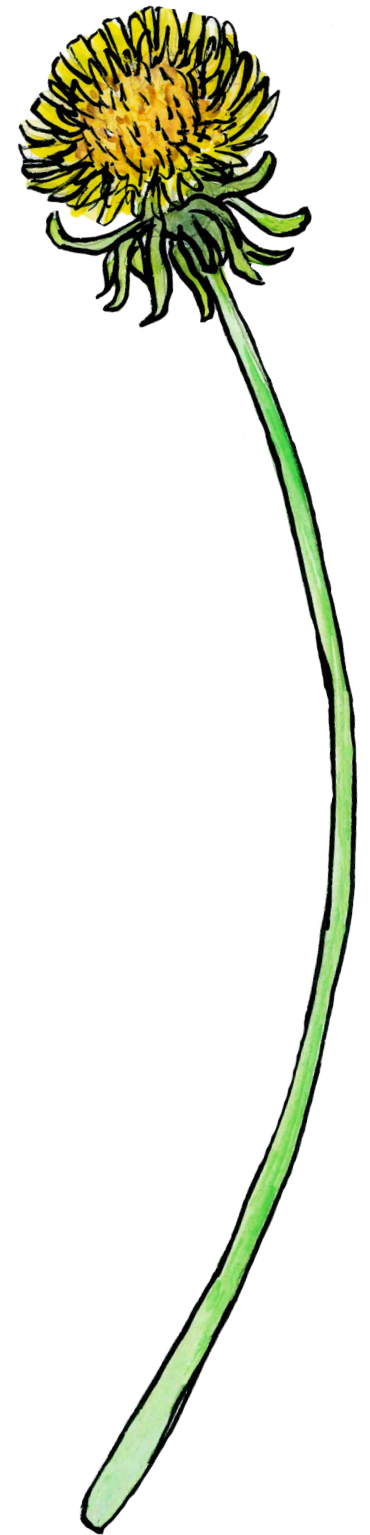
“Since opening in 2005, the Leo Fung Center for CAH and DSD has the distinction of being the first clinic in the country where providers from many specialties work together in a single clinic location to care for patients with CAH and DSD.” (University of Minnesota, 2014)

Children and Youth with Special Health Needs Section of the Minnesota Department of Health

“[Our vision is] To improve population health through building the capacity of all systems that serve families of children and youth with special health needs.” (Minnesota Department of Health, 2015)

Family Voices of Minnesota

“Family Voices aims to achieve family-centered care for all children and youth with special health care needs and/or disabilities.” (Family Voices, 2015)





Minnesota Department of Health
Children and Youth with Special Health Needs Section

www.health.state.mn.us/cyshn

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2015

