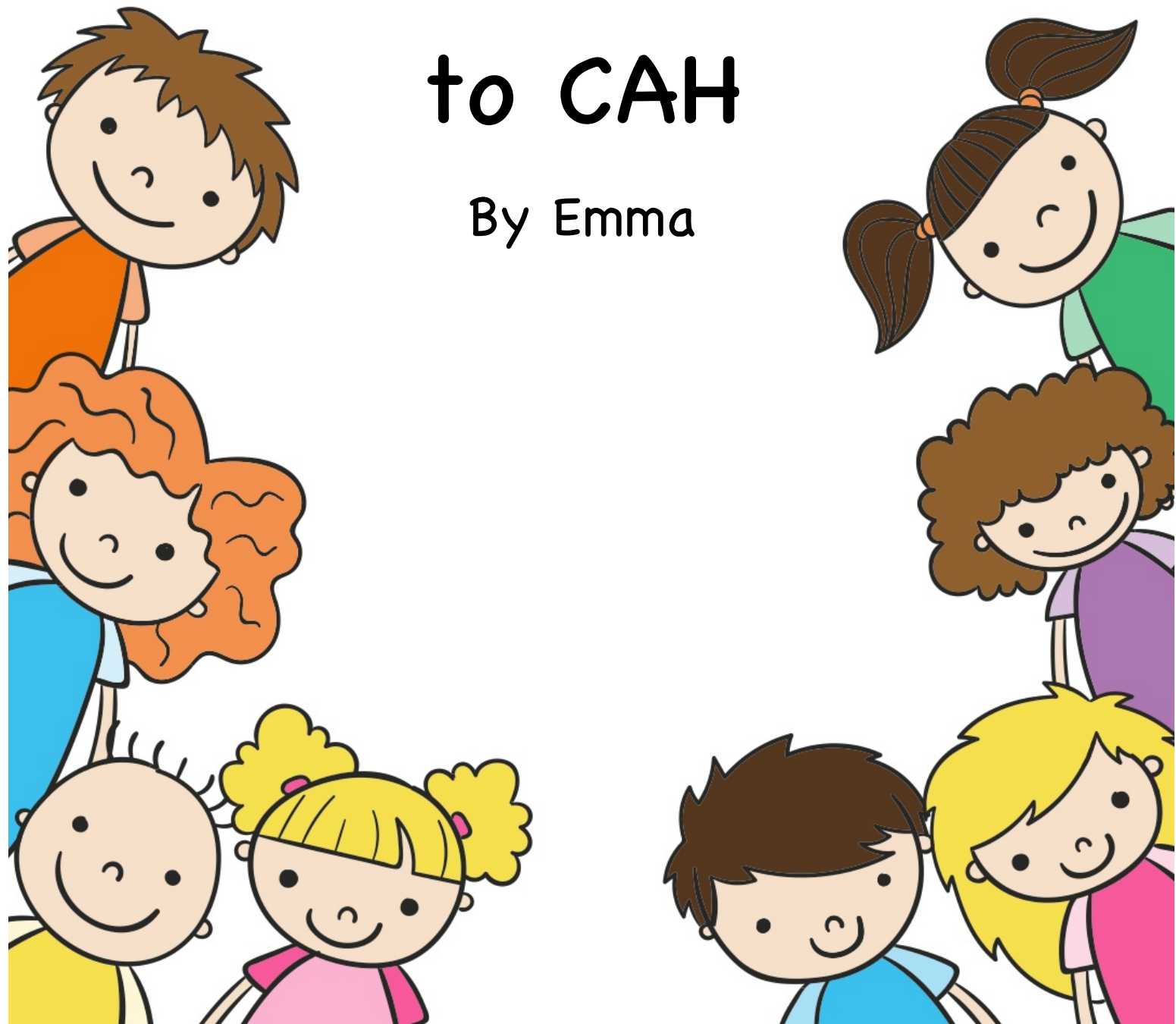


A Girl's Guide to CAH

By Emma

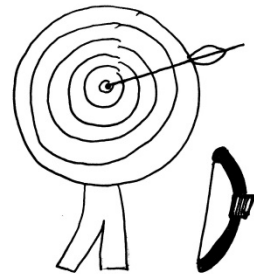
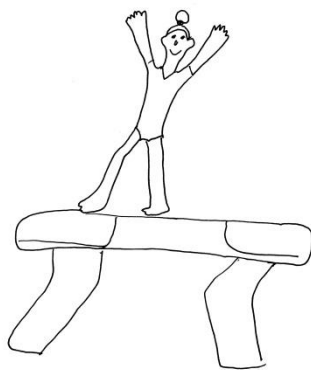
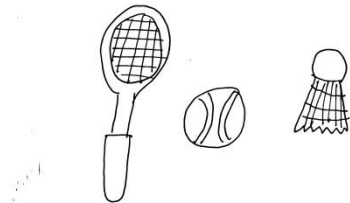


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This is Me

My name is Emma. I am 10 years old. I love swimming, gymnastics, archery, sewing and making models, especially of old cars. My papa has also taught me lots about old radios. Sometimes we clean them up and get them working again. I often go to car boot sales with my mum and dad to find old radios.



My sister and I go to the local primary school. I have good friends there and after primary 7 I will move to Secondary school. My favourite subjects are Maths and Science. I want to be a doctor when I grow up. I might be a consultant. My mum says that I have wanted to be a doctor since I was 2 years old. My sister and I love to play doctors with our teddies (I still like to play even though I am 10!). Our teddies and sometimes our dog are the patients. We pretend to take bloods and put 'lines' in. I learnt this at the hospital that I go to sometimes because I have a medical condition called Congenital Adrenal Hyperplasia, or CAH for short.

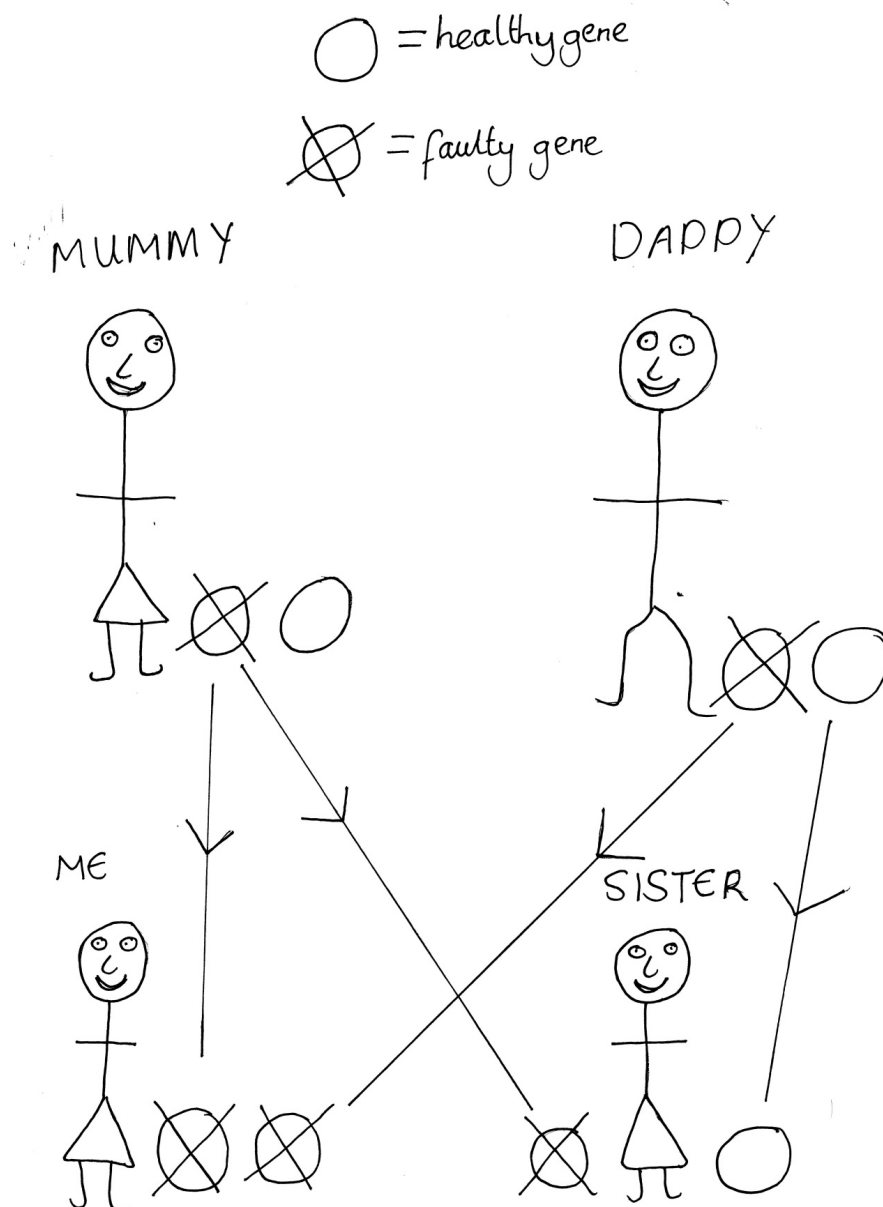
What is CAH?

Most people have never heard of this condition because it is quite rare, not many people have it. So, I am pretty special! Some of my friends have medical conditions. Harry has diabetes, so he has to be careful not to eat too much sugar. James has autism, so he doesn't like too much noise and understands things better in pictures. No one else in my school has CAH, although I do know a few other people who also have it. Our parents meet up sometimes and it is fun to meet someone else who takes the same medicine. I take tablets 3 times a day. One tablet helps my body to keep salt inside and the other is to replace 'cortisol' in my body. Cortisol is really important for the body. If someone gets sick, like a high temperature or a tummy bug, his or her body would naturally make more cortisol. My body can't so I have to take more whenever I get sick.

Mum says that CAH is a complex medical condition. That means that it is difficult to understand and it can affect my body in different ways. I will explain to you how I understand it. This is my version of CAH.

How did I get CAH?

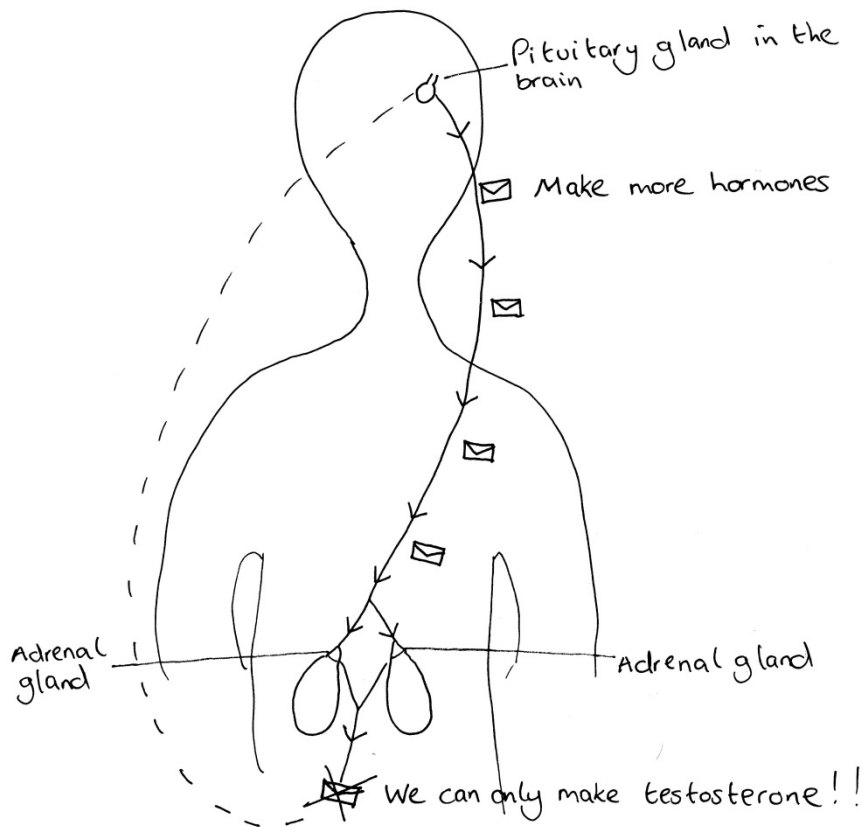
Firstly, CAH is a genetic condition. This means that my mum and dad both carry the faulty gene that causes CAH. We are all made up of a huge, complicated variety of genes that we get from our parents. There is one specific gene that causes CAH. My mum and dad each have 2 copies of this gene, one works and one doesn't. I got the faulty one from my mum and the faulty one from my dad that means that I have CAH. My sister got the faulty one from my mum but the working one from my dad, which means that she also has a faulty gene but does not have CAH. All very complicated, I know!! I have drawn a diagram that helps me understand it better.



CAH started to affect me when I was inside my mum's womb, before I was even born. It gets even more complicated now!

Everyone has 2 adrenal glands in their bodies. They sit on top of the kidneys and usually produce 3 things called 'hormones' which help the body to work properly. However, because I have CAH my adrenal glands cannot make 2 of these hormones. Like I said before, one keeps salt in the body and the other makes 'cortisol' which helps the body to deal with stress.

A special part of the brain sends messages to the adrenal glands to make the 3 hormones, but the adrenal glands cannot send any messages back to the brain to say that they are not working properly. So when someone has CAH their adrenal glands make too much of the 1 hormone that it can make. This is called 'testosterone'.



CAH and genitals

The clitoris

In the first few weeks of life a baby's genitals form - the vagina for girls and the penis for boys. When this is happening girls also get a clitoris, a soft lump outside the vagina. Like all parts of the vagina it is a different size for all girls but for girls who have CAH it is usually quite large. This is because of all the extra testosterone girls with CAH get when in their mum's womb. Usually girls only get a small amount of testosterone and boys get more. I don't mind that my clitoris is large, that's just the way it is. I didn't even know until mum explained this to me recently. She says this is the way I am meant to be and I am perfect just the way I am. Mum says there is no 'right' way a vagina should look as all women are different shapes and sizes, we just don't realise because this is a private part of our bodies. When I am older I could have an operation to make the clitoris smaller, if I want to.

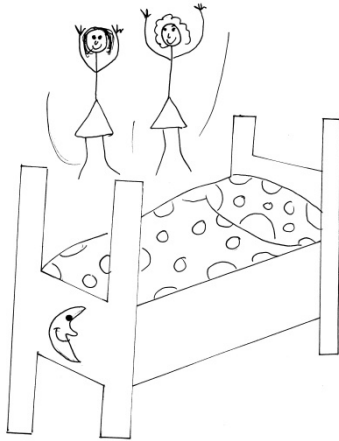
The vagina

Girls with CAH may also have a small vagina and may need an operation when they are older to make this bigger. I will need this if I want to use tampons when I have a period. This is when blood comes from the womb and out of the vagina. This happens for around 5 days once a month. Mum says it is up to me to decide when I am older when I want to have an examination and possible operation. A surgeon would have to look inside my vagina to find out if I need an operation and what he would need to do. I find this all quite scary but mum says that we can talk through it all when I am older and can understand more about it. She tells me that it is my body so I have to decide what is best, although she and the doctors can help me.

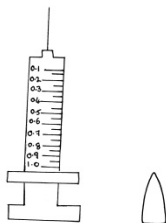
CAH does not affect any of the other 'bits' girls have inside, so I have ovaries and a womb and should be able to have babies.

CAH and getting sick

Having CAH is ok. I don't mind the tablets. When I go to places without my mum or dad I have to take an emergency kit with extra hydrocortisone medicine. At parties mum explains to my friends' mums about my condition, just in case I have a bad fall and break an arm, or something. I broke my elbow once. My sister and I were jumping from our window on to the bed, but I bounced off and landed on the floor! It sounds funny now, but it wasn't then. It really hurt.



When you hurt yourself really bad your body is shocked and needs to make more of the 'cortisol' hormone to help with the shock. As I have CAH my body cannot make cortisol so my mum had to give me extra tablets when I hurt myself. I also need to take extra if I have a high temperature or a tummy bug. In my emergency kit I also have suppositories. This is like a big tablet that is put into the bum! This is used if I am unconscious or cannot take tablets. It sounds really yuck but doesn't hurt and is better than getting really sick. Some people have an injection kit instead of suppositories.



Sometimes, I have to go to hospital when I have a really bad tummy bug and vomit too much. Mum says that when I am older I will have to take responsibility for my own tablets and to remember that if I am sick or hurt myself I can get very tired and very ill quickly. If I don't take extra tablets or go to the hospital then I can get very, very sick.

CAH and Me

Just because I have CAH doesn't mean it affects the way I live. Just because I have to take tablets doesn't mean that I can't do a certain thing. It doesn't make a difference to who I am - I am unique.



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