Tuberous Sclerosis Complex



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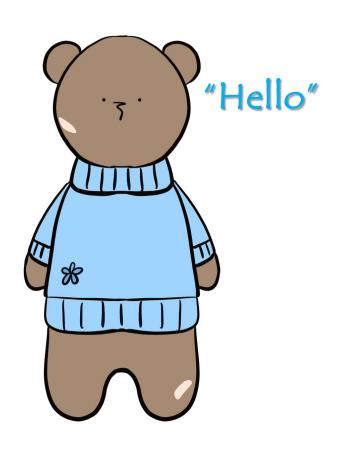
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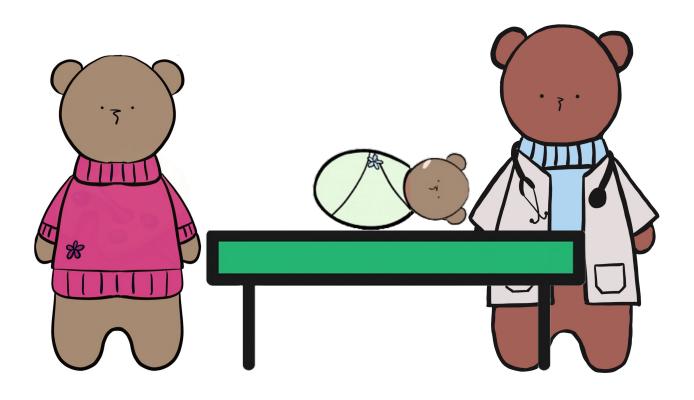
Hello, how are you? Did you notice that I have a few birthmarks? Do you think I look different?



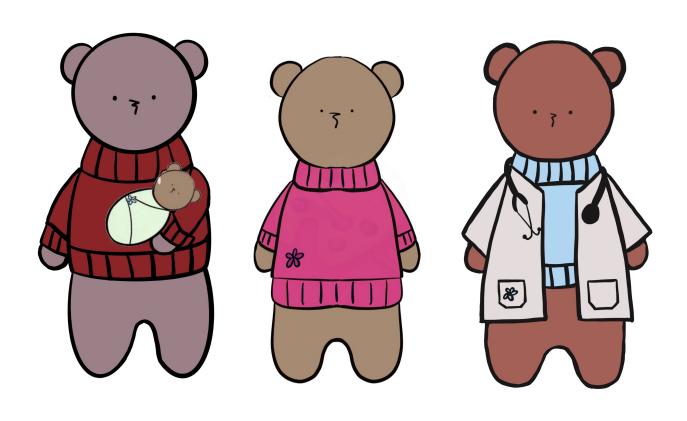
When I was born, the doctor noticed that I had some birthmarks on my skin. My parents thought they were really cute, but the doctor said that I needed to see a birthmark specialist.



My parents took me to a very nice doctor. After a few tests, the doctor explained that I have Tuberous Sclerosis Complex.



Tuberous Sclerosis Complex (TSC) is a genetic condition that can affect multiple parts of the body, especially the skin, heart, kidney, lungs, and brain.



The doctor explained that:

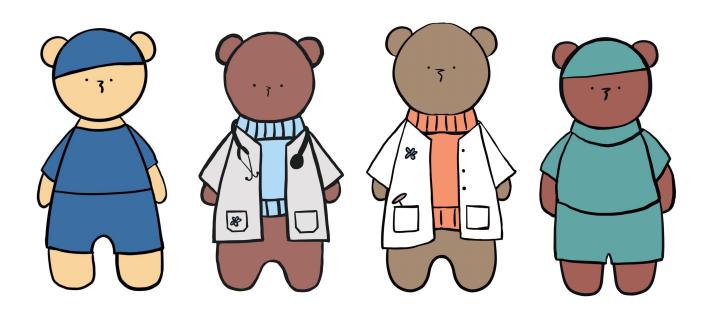
- We are born with tuberous sclerosis, so you cannot "catch it."
- TSC is caused by mutations in either *TSC1* or *TSC2* genes.

 Symptoms are very different between people with TSC, even people within the same family.

 People with TSC need frequent tests to help keep them healthy. At first, my parents were scared, but the nice doctor explained that there is a lot they can do to help people with Tuberous Sclerosis Complex.



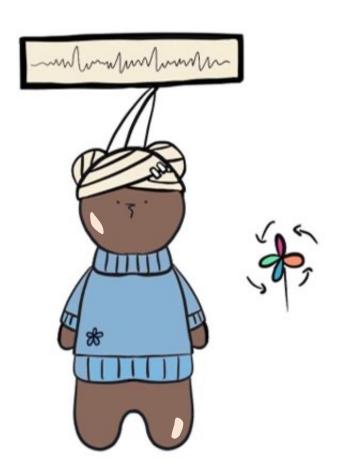
Brain doctors (neurologists), kidney doctors (nephrologists), heart doctors (cardiologists) and skin doctors (dermatologists) will help control the symptoms of TSC and make me feel better.



Sometimes I get a picture of my brain and belly called an MRI. It doesn't hurt; I just need to be very quiet and try not to move. Sometimes I get a medicine to help me sleep so that I don't move.

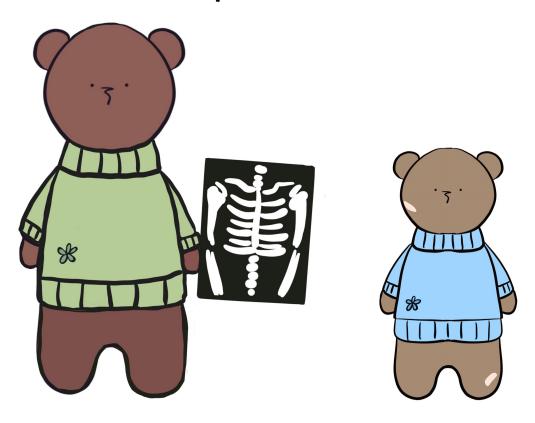


Sometimes I also get an electroencephalogram (EEG) to help check if I have a higher chance for having seizures. Some people with TSC have seizures and take a medication to help control them.

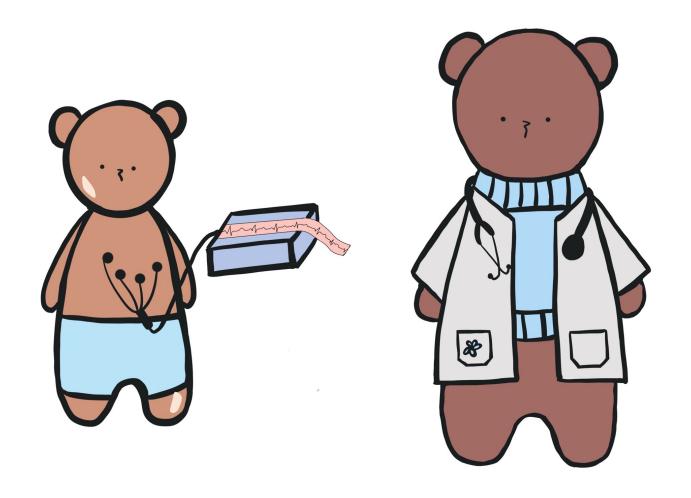


Getting an EEG is funny because they put several wires on my head. I have to blow on a pinwheel and lay down quietly. Just like the MRI, it doesn't hurt.

I also sometimes get x-rays. These are simple pictures of my body. They always show the x-rays to me and I can see my bones! It is really cool.



Sometimes I need a blood test (this part is not very fun). I also sometimes need a heart test called an EKG. It doesn't hurt.



In the beginning, I thought I was the only person with Tuberous Sclerosis Complex, but now I know that although the condition is rare, many people also have it.

Everyone with TSC has different signs and symptoms.

Although I have birthmarks and maybe some other things, I am a regular kid, just like you!



The End

