

Spinal Muscular Atrophy



Marie Sweatt, MD

Maria Augusta Montenegro, MD, PhD

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Department of Neurosciences

Division of Pediatric Neurology

Rady Children's Hospital / UC San Diego

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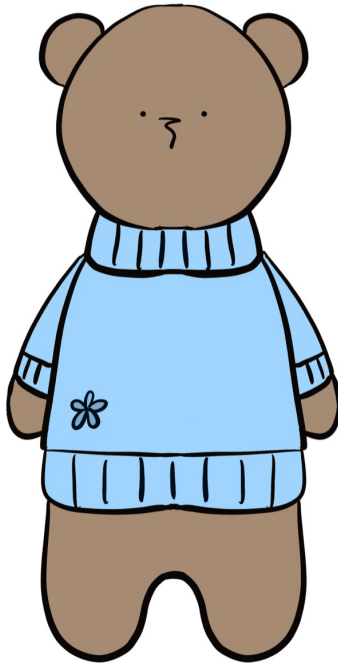
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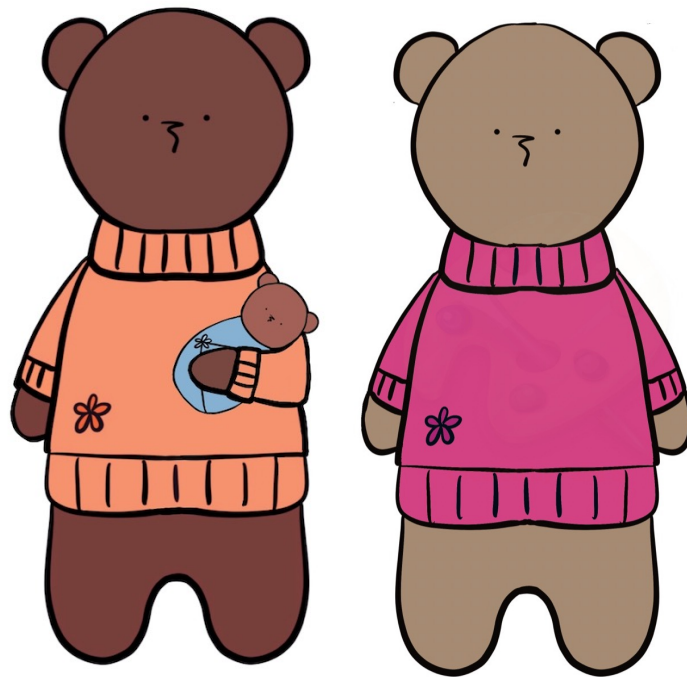


Hello, how are you? Did you notice something different? Not really right? But I want to tell my story.

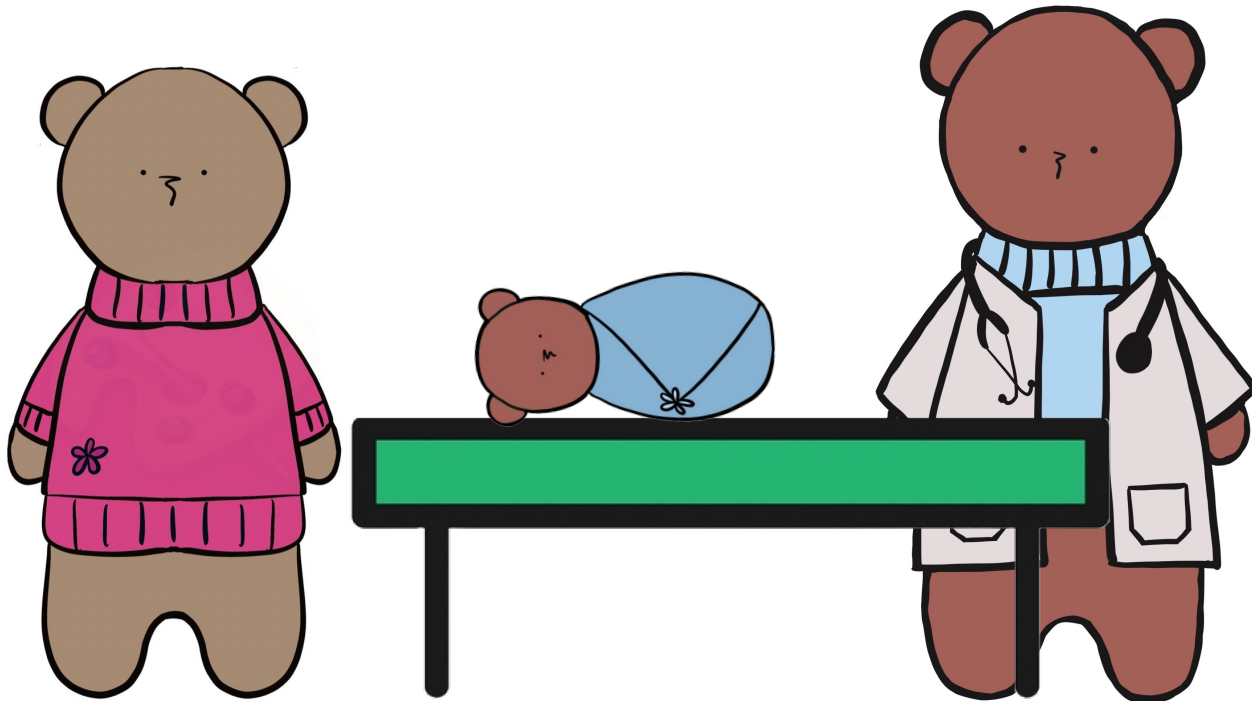
"Hello"



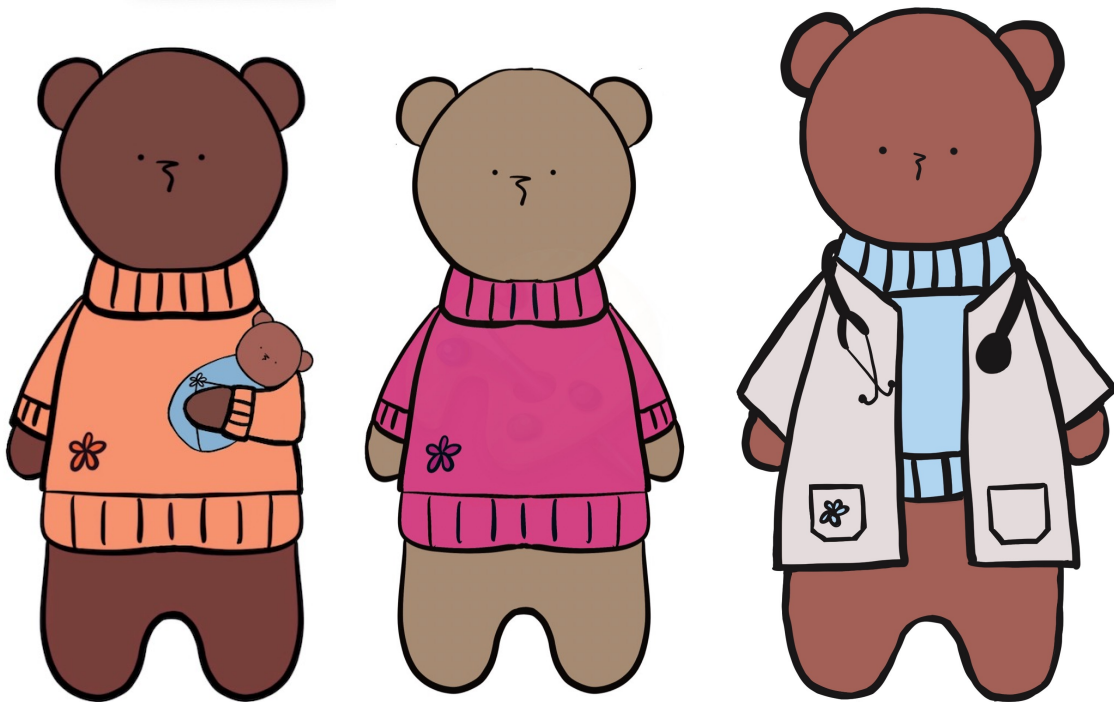
When I was born, the doctor noticed that I was a little floppy. My parents thought it was really cute, but the doctor said that we needed to see a muscle specialist.



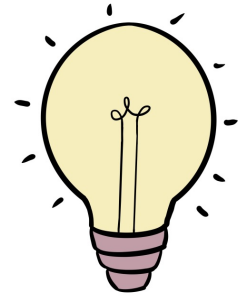
My parents took me to a very nice doctor. After a few tests, the doctor explained that I have SMA (Spinal Muscular Atrophy).



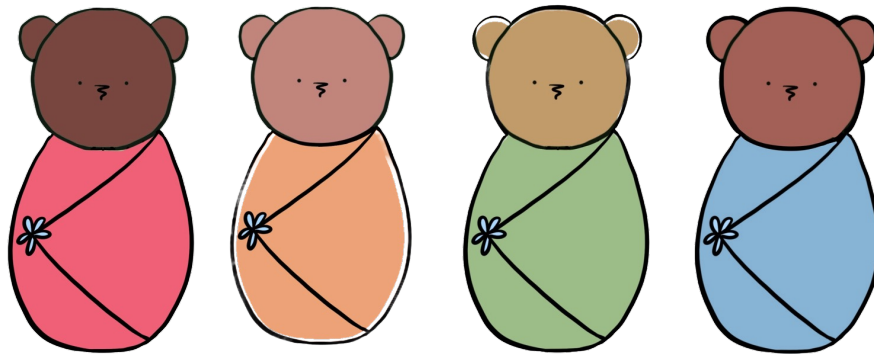
The doctor explained that:
SMA is a genetic condition that affects the
motor neurons in our spinal cord. It impairs
the connection between nerves and muscle.



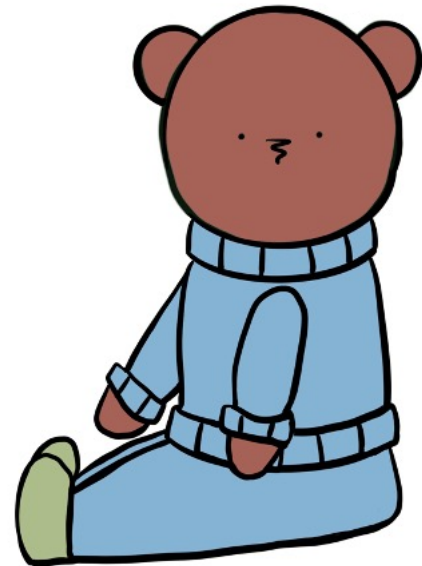
- Motor neurons connect to muscles like a light switch connects to a lamp. Without the motor neuron, the muscle cannot be turned on.



- We are born with spinal muscular atrophy, so you cannot "catch it".
- SMA is caused by mutations in the SMN1 gene.



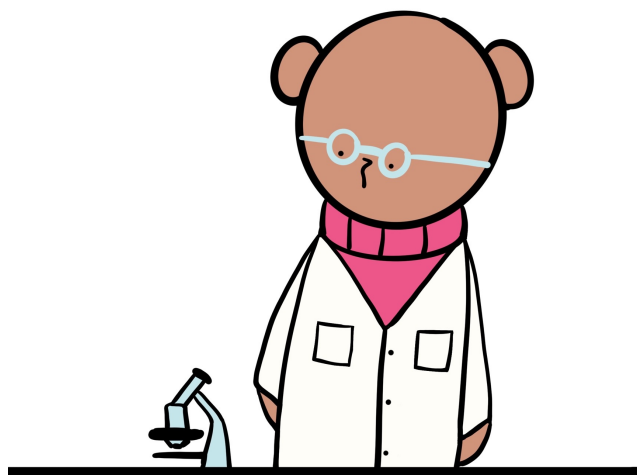
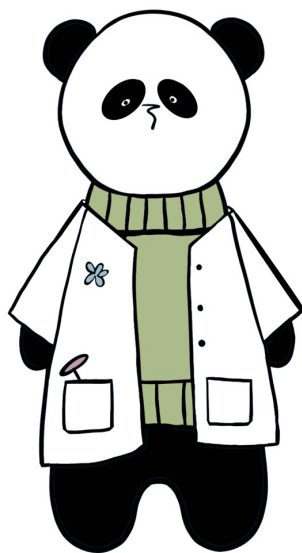
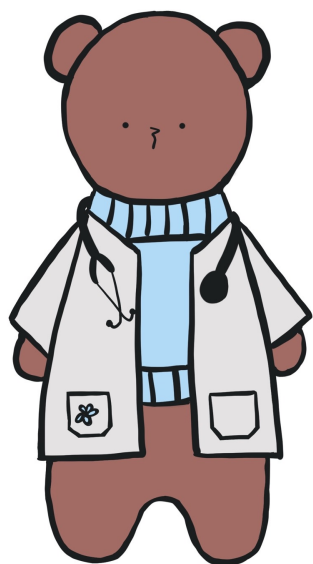
- Symptoms vary and it may start very early in life, during the newborn period.
- Others will have symptoms only during childhood.
- The most common symptom is weakness and that's why some children with SMA have difficulty sitting up or walking.



At first, my parents were scared, but the nice doctor explained that there is a lot they can do to help people with Spinal Muscular Atrophy.



There is still a lot to know about SMA and scientists are working hard to find out how to treat it even better.



Currently, there are several treatment options.

- Physical therapy.
- Medication that you take every day by mouth.
- An injection that is given at the hospital.

These medications protect the motor neurons and keep the muscles strong.

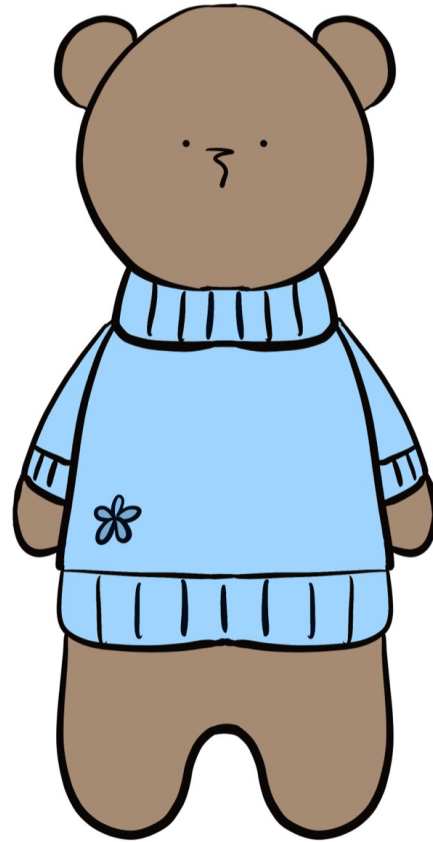
There is also a **gene therapy** in which doctors can add a normal SMN1 gene into the cells with the help of a virus.



In the beginning, I thought I was the only person with SMA, but now I know that although rare, many people also have it.



Everyone is a little different and although many kids have a muscle disease we are a regular kid, just like you.



The End

