Duchenne Muscular Dystrophy



Marie Sweat, MD Maria Augusta Montenegro, MD, PhD Spinal Muscular Atrophy First edition, 2024 Text Copyright by Maria A. Montenegro & Marie Sweat Illustrations Copyright by Maria Carolina Montenegro

Department of Neurosciences Division of Pediatric Neurology Rady Children's Hospital / UC San Diego

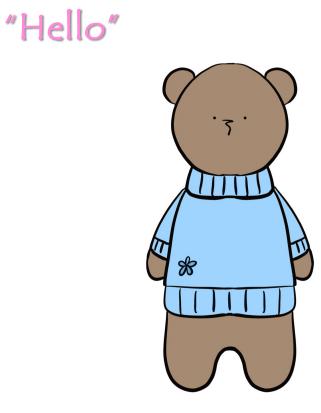


This is a work of fiction. Names, characters, places and incidents are either products of the author's imagination or, if real, are used fictitiously.

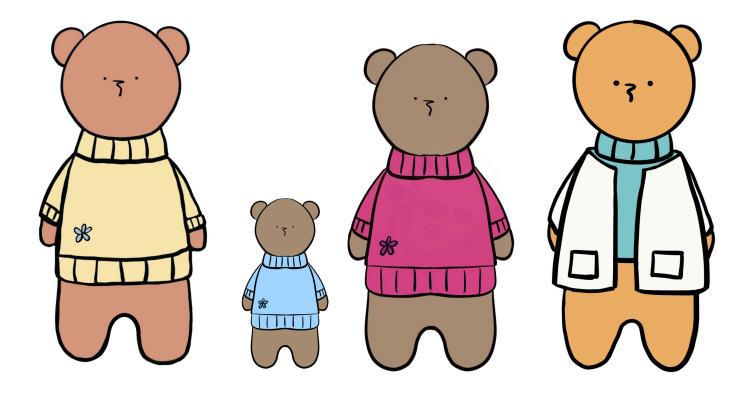
All rights reserved.

No part of this book may be used or reproduced in any means, electronic or mechanical, including any information storage and retrieval system, without written permission.

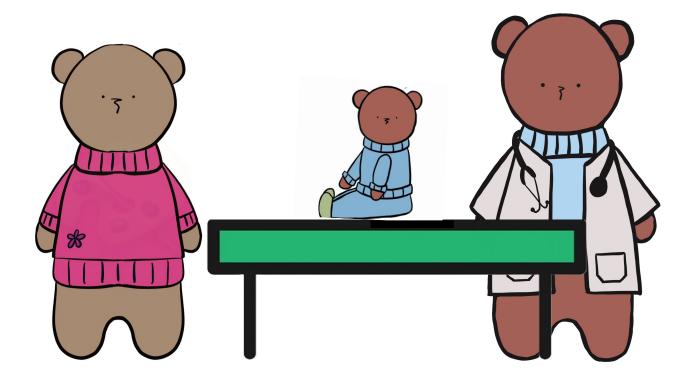
Hello, how are you? Did you notice something different? Not really right? But I want to tell my story.



When I was little my parents noticed that I had a hard time climbing stars. At the begging they thought it wasn't anything serious, but my pediatrician told them that I needed to see a neurologist.

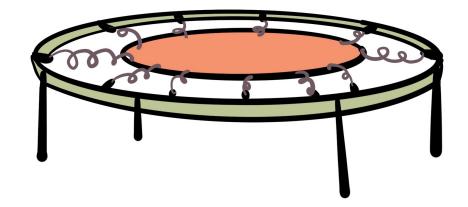


My parents took me to a very nice doctor. After a few tests, the doctor explained that I have Duchenne Muscular Dystrophy.



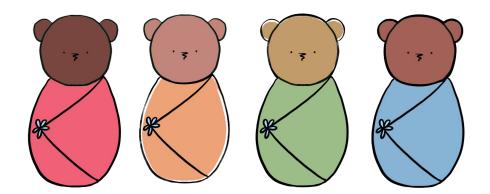
Duchenne muscular dystrophy is a genetic condition when a protein called dystrophin is missing. Dystrophin stabilizes the muscle cell membrane like a coil stabilizes a trampoline. If it doesn't work well, the muscle cell might break.





The doctor explained that:

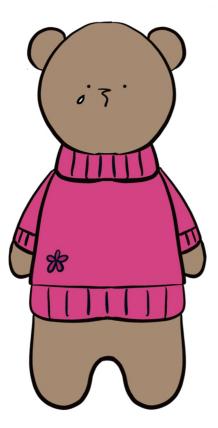
We are born with Duchenne Muscular Dystrophy, so you cannot "catch it".
It is caused by mutations in the DMD gene.
Symptoms vary but it usually starts in the first years of life.



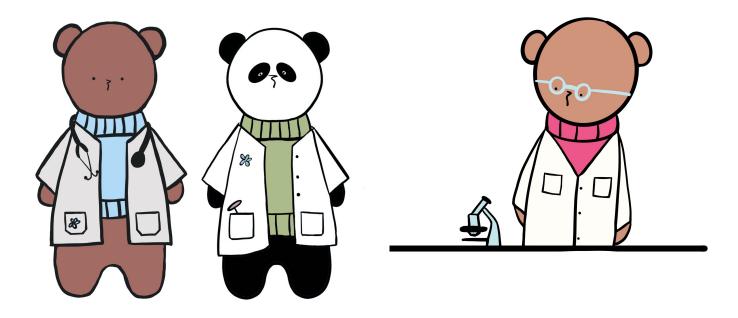
- The most common symptom is weakness causing it difficult to climbing stars or standing up.
- Duchenne Muscular Dystrophy may also affect the heart, so we patient's need regular check ups.



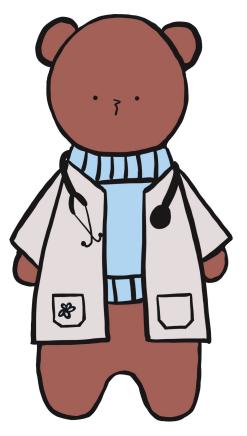
At first, my parents were scared, but the nice doctor explained that there is a lot they can do to help people with Duchenne Muscular Dystrophy.



There is still a lot to know about Duchenne's Muscular Dystrophy and scientists are working hard to find out how to treat it even better.



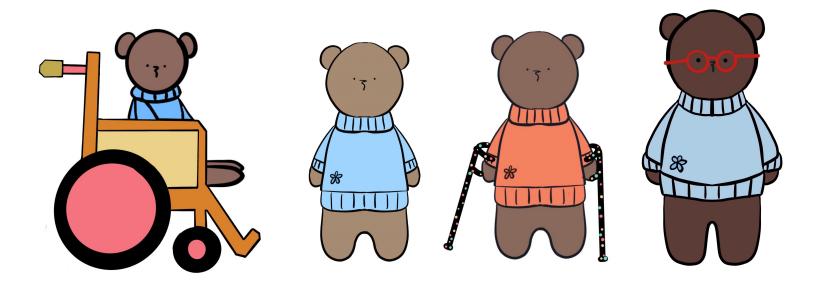
- Currently there are several treatment options.
- The most common is steroids, which keep the muscles healthy.
- Others are weekly infusions, which help the body make dystrophin.
- Physical therapy and exercise, like as biking and swimming, can also help.



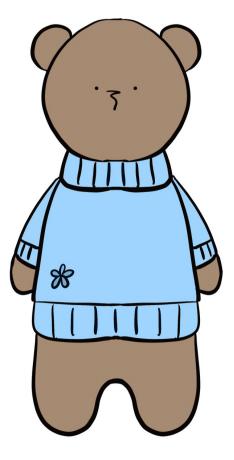
There is also a gene therapy in which the doctor gives a small version of the DMD gene with help of a virus.



In the beginning, I thought I was the only person with Duchenne Muscular Dystrophy, 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

