DMD and Me

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To learn more about Duchenne muscular dystrophy, including how you can join the fight, visit ParentProjectMD.org.

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My name is Chris. This is my family. I have a mom, a dad, a big brother named Joey, and a dog named Jake.
I also have DMD, which means “Duchenne Muscular Dystrophy”.
When I was little, my parents noticed that I didn’t move the same way that Joey did when he was little. I could think, talk, laugh, smile, and play just like Joey,
but I didn’t crawl the way he did. I crawled by pulling myself with my arms.

Joey started walking when he was one year old. I started walking when I was one and a half years old.

Sometimes I walked on my tiptoes. I couldn’t run fast because my legs weren’t very strong.
I fell down more often than Joey ever did, but I always got up again!

When Joey went upstairs to play, I would follow him by crawling up the stairs like a mountain climber.

When Joey came back down, I was right behind him bump, bump, bumping on my rump!
My parents took me to Children’s Hospital and a nice doctor did some tests.
She moved my arms and legs and I showed her how strong I was.

She tapped on my knees to see if my legs would kick.

She asked me to sit on the floor and get back up. It took me longer than it takes Joey, but I did it!
After all the tests, the doctor told my parents that I have DMD.

She said that my muscles don’t have enough of something called dystrophin.

Dystrophin helps muscles grow and keeps them strong.

My mom and dad looked sad when they heard the news.
I didn’t feel any different. When I looked in the mirror, I didn’t look any different. I didn’t feel sad or mad or glad.
Having DMD is not my fault.
It’s not anybody’s fault.

Now I know why it is hard for me to keep up with Joey and my friends.

I’m not lazy.
I’m not sick.
I’m not bad.
Other kids cannot get DMD from me. It doesn’t work that way.
It’s not like having a cold.

It is deep inside of me and I can’t sneeze it, or blow it, or cough it out.
My favorite color is orange. I like playing with my friends and making things. I especially like drawing pictures of robots and mazes. I read books about dinosaurs, race cars, trucks, and bugs. My favorite things at school are Science, Music, Art, and Recess.
I have to be careful on the playground so I don’t get knocked down. Some kids don’t understand that because I have DMD,

I can fall if they bump into me.
I have been friends with Sara my whole life. We like a lot of the same things. Sara’s favorite thing is jumping rope.
When I try to jump, my right foot goes up when my left foot goes down. My doctor said it’s probably best if I don’t jump, so Sara said I could be her coach. I count out loud as she jumps:

2 4 6
1 3 5 7

We make a great team!
Joey and I have a basketball hoop. We can make it high or low, so it is perfect for both of us.

Joey is good at dunking, I am good at free throwing, and Jake is good at guarding.
Someday, if it gets too hard for me to walk, I might get a wheelchair.

Our friend, Josh, has DMD too. He is older than I am and he has a wheelchair.
Josh can do all kinds of things and go lots of places with his wheelchair.

He goes to work, to restaurants, and to the movies with his friends.

The people at Children’s Hospital have helped Josh and now they are helping me.
There are many doctors, nurses, and scientists all over the world working to find a cure for DMD.
My parents take me to see one doctor for my muscles,
one doctor for my lungs,
one doctor for my heart,
and one doctor for my bones.

The doctors know what pills I can take and which exercises I can do to help me stay strong.
The physical therapist fit my legs for braces and showed us how to do some stretches at home. Mom and Dad help me with them and Joey counts out loud for me.

Now he’s my coach!
My whole family has learned a lot about DMD and most important of all, we know it is just a little part of who I am.
A Popping Wheelies Picture Book