## **Duchenne Muscular Dystrophy (DMD)**

## What is Duchenne Muscular Dystrophy (DMD)?<sup>1</sup>

DMD is caused by a genetic mutation, which prevents the body from making dystrophin.

# What are terms that I might hear my doctor use when talking about DMD?<sup>1</sup>

**Dystrophin:** This is the protein that is lacking in the body with DMD. *Dystrophin* is created to help your muscles work properly.

**Contracture:** Because the muscles are not able to work properly, *contractures* can occur. A *contracture* of a joint means the joint is stuck in a certain position and is difficult to move. This is why flexibility exercises are important for your child.

**AFO (Ankle Foot Orthosis):** Your doctor might bring up using an *AFO* with your child. This is just a fancy term for a brace that goes on your child's foot. Using an AFO can help prevent contractures and/or help your child walk better. See the "Equipment Use" tab on this website for further details on *AFOs*.

## What are some signs of DMD?1

Early signs and symptoms may include but are not limited to delayed sitting, delayed standing, and delayed walking. Those with DMD might not begin walking until 18 months, have larger calf sizes, walk on hands to get to a standing position, walk on their toes, and have frequent falls. It is important to realize signs/symptoms may vary from child to child. Just because a child exhibits these signs/symptoms does not automatically mean a child has DMD. Consult with your doctor if you have any concerns. For more signs/symptoms, visit <a href="Duchenne Muscular">Duchenne Muscular</a>
<a href="Dystrophy: The Basics">Dystrophy: The Basics</a>.

#### What can physical therapy do for children with DMD?

Physical therapists are movement specialists and will tailor treatment to your child's specific movement needs. In general, physical therapy can help children with DMD stay FLEXIBLE and MOBILE. Physical therapy can also work with and educate parents/caregivers on appropriate, safe activities to do at home in order to help your child.

#### What activities can I do with my child?2

Stretching can help your child remain flexible and prevent contractures. See the pdf below for stretching ideas. Children with DMD can remain active and light exercise should be encouraged!

Too much exercise can damage your child's muscles. *Because of this, your child should not exercise to the point of exhaustion.* Swimming and water activities can be helpful for children with DMD. See ideas for water activities here: <a href="Pool activities for those with Duchenne">Pool activities for those with Duchenne</a> <a href="Queence-ne">Queence-ne</a>. If you have any questions or concerns about what activities you should and should not do with your child, please consult your physician or physical therapist.

#### **DMD Resources**

Having a child with DMD can be difficult, but YOU ARE NOT ALONE! See this resource for support groups and community resources: <u>Ways to Connect</u>. Camps can also be great for your child: <u>MDA Summer Camp</u>.

#### Sources

- 1. <a href="https://www.duchenne.com/about-duchenne">https://www.duchenne.com/about-duchenne</a>
- 2. <a href="https://www.mda.org/disease/duchenne-muscular-dystrophy/medical-management">https://www.mda.org/disease/duchenne-muscular-dystrophy/medical-management</a>