

# Duchenne Muscular Dystrophy

## FACT SHEET

### What is Duchenne muscular dystrophy?

Duchenne muscular dystrophy (DMD) is a genetic disorder that causes muscles to gradually weaken over time. A person with DMD will eventually lose the ability to walk and will have problems with breathing and his or her heart. It most often affects boys and occurs among all races and cultures. Sometimes this disorder affects other members of a person's family, but in many cases it is new to a family.

### What are the signs of DMD?

A child who has DMD does not reach certain developmental milestones at the same time as other children of the same age, particularly motor or movement milestones. Most boys with DMD start walking later than other children and are thought to be clumsy and fall a lot. In some cases a child might have learning and speech delays.

#### Children with DMD might:

- Not be able to walk by 15 months of age
- Walk with the legs apart, on the toes, or walk with the belly pointed out (also called lordosis), or both
- Fall frequently
- Need help getting up from the floor or "walk" up their legs with their hands in order to stand (also called Gowers maneuver)
- Have difficulty with motor skills such as running, hopping, jumping, or climbing stairs
- Have larger calves than other children of the same size or age (also called pseudohypertrophy)
- Frequently complain of having tired legs
- Have behavior and learning difficulties
- Have delayed speech

*Most children with motor or movement concerns do not have DMD, but should still be seen by a health care professional.*

### What causes DMD?

Children who have DMD make no or low amounts of a protein called dystrophin. Dystrophin acts like glue,

holding muscles together by keeping the structure of muscle cells. Without it, muscles weaken over time and become unable to work properly.

### How and when is DMD diagnosed?

A simple and inexpensive blood test called creatine kinase (CK) can help make the diagnosis. If the test results are positive, the doctor might order additional tests. DMD is usually not identified until a child is 3 to 6 years of age, but can be diagnosed earlier.

### What can I do if I think my child might have DMD?

Talk with your child's doctor or nurse. If you or your doctor think there could be a problem, ask for a referral to see a developmental pediatrician, neurologist, or other specialist and contact your local early intervention agency (for children younger than 3 years of age) or public school (for children 3 years of age or older) to find out if your child qualifies for intervention services. To find out whom to speak to in your area, you can contact the National Information Center for Children and Youth with Disabilities at [www.nichcy.org/states.htm](http://www.nichcy.org/states.htm) or call the Centers for Disease Control and Prevention (CDC) at **1-800-232-4636**. In addition, CDC has links to additional information for families on their Duchenne muscular dystrophy webpage at [www.cdc.gov/ncbddd/duchenne](http://www.cdc.gov/ncbddd/duchenne).

If your child is diagnosed with DMD, there are many groups that can help you, including the Parent Project Muscular Dystrophy: <http://www.parentprojectmd.org> and the Muscular Dystrophy Association: <http://www.mda.org/>.

To help a child with DMD reach his full potential, it is very important to get help for him as early as possible. Acting early can make a real difference!

[www.cdc.gov/actearly](http://www.cdc.gov/actearly)



Learn the Signs. Act Early.