



INCLUSIVE 4-H



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# Youth and Muscular Dystrophy

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## What is Muscular Dystrophy?

Muscular dystrophy is the name used to categorize many diseases that weaken and degenerate the muscles. It is a progressive disease, meaning that it worsens over time. Each type of muscular dystrophy has its own specific symptoms, time of onset, and severity. Some types affect males almost exclusively while other types affect males and females equally.

## What Causes Muscular Dystrophy?

Muscular dystrophy is a genetic disease caused by alterations on specific genes. These alterations create little or no production of proteins that maintain muscles. This causes the weakening and degeneration. It is an inherited disease that it is passed on genetically from parents to children. However, one can be a carrier and not actually have muscular dystrophy. There is no cure for muscular dystrophy, but genetic testing can be done to determine if one is a carrier.

## What Are the Types of Muscular Dystrophy?

There are nine major types of muscular dystrophy. Other rare types do exist. Below are the names and descriptions of the nine major types:

1. **Duchenne Muscular Dystrophy (DMD)**—Symptoms normally occur by 2 to 6 years of age and begin with weakness and degeneration in the muscles in the limbs and trunk. Eventually it will affect all voluntary muscles. The calf muscles are often enlarged. The progression is slow, but survival is rare past the late 20s. This type affects males primarily. Females rarely have this form of muscular dystrophy. It is also known as pseudohypertrophic muscular dystrophy.
2. **Becker Muscular Dystrophy (BMD)**—Symptoms can begin during adolescence through adulthood. The symptoms are the same as DMD but are less severe. Progression is slow, and the survival rate is from mid to late adulthood. This type affects primarily males. Females rarely have this form.
3. **Emery-Dreifuss Muscular Dystrophy (EDMD)**—Symptoms begin to appear between childhood and the early teenage years. It begins with weakness and degeneration of the shoulder, upper arm, and shin muscles. Joint deformities may also be present. Heart complications may appear in later stages of this type. It progresses slowly. It also affects primarily males, while females are afflicted on rare occasions.

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4. **Limb-Girdle Muscular Dystrophy (LGMD)**—Symptoms begin between late childhood and middle age. This type is characterized by weakness and degeneration of the shoulders and pelvic girdle. Heart and lung complications may be present in later stages. This type progresses slowly. It affects both males and females equally.
5. **Facioscapulohumeral Muscular Dystrophy (FSH)**—Symptoms begin to appear between childhood and early adulthood. FSH is characterized by weakness and degeneration of facial and shoulder muscles. The progression of this type is slow with some rapid periods of deterioration. It affects both males and females. It is also known as Landouzy-Dejerine muscular dystrophy.
6. **Myotonic Dystrophy (MD)**—Symptoms start to appear anywhere from birth to middle age. This type affects the muscles of the face, feet, hands, and neck. Muscles may experience delayed relaxation. This may make letting go of objects on demand difficult. This type of muscular dystrophy progresses very slowly, sometimes spanning 50 to 60 years. Infants who display this type will most likely be mentally retarded. MD affects both males and females. It is also known as Steinert's disease.
7. **Oculopharyngeal Muscular Dystrophy (OPMD)**—Symptoms begin to occur from early adulthood to middle age. Eyelid and throat muscles are affected. Progression is slow, but serious problems with swallowing occur as this type progresses. OPMD affects both males and females.
8. **Distal Muscular Dystrophy (DD)**—Symptoms of this type do not typically appear before the age of 40 to 60 years. It affects the muscles in the hands, forearms, and lower legs. The progression is slow. DD is not life threatening. It affects both males and females.
9. **Congenital Muscular Dystrophy (CMD)**—Symptoms are present at birth in this type of muscular dystrophy. There is generalized muscle weakness and degeneration as well as joint deformities. The progression of this type is slow, but mental functions may be affected. Both males and females are affected.

## **What is the Treatment for Muscular Dystrophy?**

Treatment includes exercises that stretch muscles and promote a range of motion. Aquatic workouts may be especially beneficial because it puts less stress on the joints. However, too much exercise can be harmful to those with muscular dystrophy. Some people may need breathing tubes, wheelchairs, leg braces, etc., to help with daily living. Heart transplants may be an option for some individuals.

## **Important Issues for Extension Educators and 4-H Leaders to Consider:**

1. Have contact information for parents or guardians and the member's doctor in accessible places. An example of this would be behind the child's nametag and in the medical forms box in the main office at 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.
2. Visit with the member and his or her family about the member's muscular dystrophy. Questions that could be asked include : "What type of muscular dystrophy do you have?" and "What types of modifications do you need in order to best participate?" These questions can lead to a more in-depth understanding of the child's disease and issues that could face leaders, educators, and others.
3. Activities that include a full range of motion, such as baseball, may be difficult for members with muscular dystrophy to participate in. Take this into consideration when planning activities.
4. Depending on the type and extent of muscular dystrophy, some individuals may need help with basic care needs such as hygiene, dressing, and feeding. Make sure that there is a qualified person present to take care of these needs.

## **For More Information Contact:**

### **Muscular Dystrophy Association—USA**

National Headquarters

3300 E. Sunrise Drive

Tucson, AZ 85718

Phone: (800) 572-1717

Web site: [www.mdausa.org](http://www.mdausa.org)

(Web site active as of May 6, 2005)

## **Acknowledgements:**

Appreciation is extended to the following reviewers: Matthew Cavedon, trustee, National 4-H Council; Terri Dawson, director, Parent Information Center, Buffalo, Wyoming; Roger Tormoehlen, head, Department of Youth Development and Agricultural Education, Purdue University; and Karen C. Williams, associate professor and head, Department of Family and Consumer Sciences, University of Wyoming.

Special thanks is also extended to David K. Carson, former professor of Family and Consumer Sciences at the University of Wyoming and Kent Becker, associate professor of Counselor Education at the University of Wyoming for comments on earlier versions of the articles in this series.

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