



Muscular Dystrophy: A Public Health Challenge

Muscular Dystrophy

- Muscular dystrophy refers to a group of inherited disorders that cause muscle weakness over time. This muscle weakness limits mobility and makes it difficult to perform many activities that are part of daily living.
- Different types of muscular dystrophy affect different muscles, have different symptoms, and vary in severity.
- Each type of muscular dystrophy can run in the family, or a person might be the first one in their family to have MD.
- Muscular dystrophy is rare, and little is known about how many people are affected by the condition.

Public Health Need

- **Variations in care.** Treatment and care for muscular dystrophy varies widely. Standardizing care means everyone should receive the same, excellent care regardless of where they are treated. Standardizing care also lessens the impact of muscular dystrophy on the individual, the family, and the healthcare system.
- **Impact on families and caregivers.** Muscular dystrophy has a significant impact on the family, whether that means moving to a different home or modifying an existing one, finding a job that offers the flexibility for a family member to be the primary caregiver, or even planning for more children.
- **Delay in diagnosis.** Some types of muscular dystrophy can take years to diagnose. This delay means missing access to medical care, a late start receiving early intervention services, and delayed access to special education resources.

What is CDC Doing?

The more CDC learns about muscular dystrophy, the more physicians, nurses, and allied health professionals can tailor their care for people living with MD so that each person can reach their full potential. For families and caregivers, understanding more about MD means having the tools to find and provide the best care for their loved ones.

- **Improving care and services.** CDC strives to make sure every person with MD is able to receive excellent, standardized care. CDC does this by updating the comprehensive care recommendations for Duchenne MD. These recommendations were originally developed in 2009 by the CDC-sponsored DMD Care Considerations Working Group. Beginning in 2014, CDC also engaged the American Academy of Neurology to develop the first evidence-based care guidelines for four other types of MD.

- **Conducting public health research.** CDC funds and manages MD STARnet, the Muscular Dystrophy Surveillance, Tracking, and Research Network. MD STARnet is the only research program designed to collect health information on everyone with muscular dystrophy living in specific areas of the United States. MD STARnet research includes new information on how common muscular dystrophy is, the use of steroids to slow muscle decline, and the mental health of those with MD.
- **Collaborating with partners.** In collaboration with the American Academy of Pediatrics, CDC has developed a web-based tool for parents <http://motordelay.aap.org/> who are concerned about the physical development of their child. Parents can identify “red flags” they see when their child stands, walks, climbs stairs, holds toys, and other activities. This project is designed to shorten the time to diagnosis. Parents are encouraged to take their concerns to their child’s pediatrician.

FUTURE OPPORTUNITIES

Although much has been accomplished, important questions remain to ensure people living with muscular dystrophy reach their full potential throughout their lives.

- Physicians, nurses, and allied health professionals need to have the most current scientific information to diagnose, care for, and treat their patients living with MD.
- People diagnosed with MD as children should expect to make a successful transition to adulthood. This means addressing their education, employment, housing, transportation, adult health care, and social needs to achieve a smooth transition from adolescence to adulthood.
- Newborn screening is an area of rapid scientific development. CDC contributes to this work by consulting with national leaders who are working toward developing and implementing newborn screening for Duchenne muscular dystrophy.
- Additional public health research can provide insights into the course of the disease, including care and treatment that improves the length and quality of life for those living with MD.
- Support services and assistive technologies like lifts, bathroom aids, and power scooters are used by people with MD. MD STARnet data is beginning to yield important information on how the use of these services and aids may be influenced by race or ethnicity, education level, or where the person lives. Having this information will help determine who needs these resources.

Duchenne muscular dystrophy is the most common form of muscular dystrophy in children. Symptoms include muscle weakness starting in the legs and arms, and eventually affecting the heart and lungs. Becker muscular dystrophy is similar to Duchenne, but the muscle weakness may start later and progress more slowly.

According to data from six MD STARnet study sites, an estimated 1 in every 7,250 males aged 5 - 24 years had a diagnosis of Duchenne or Becker muscular dystrophy in 2010.

Romitti PA, Zhu Y, Puzhankara S, James KA, Nabukera SK, Zamba GKD, Ciafaloni E, Cunniff C, Druschel CM, Mathews KD, Matthews DJ, Meaney FJ, Andrews JG, Caspers Conway KM, Fox DJ, Street N, Adams MM, Bolen J, on behalf of the MD STARnet. Prevalence of Duchenne and Becker Muscular Dystrophies in the United States. *Pediatrics*. 2015 March; 135(3):513-21.

