

MD

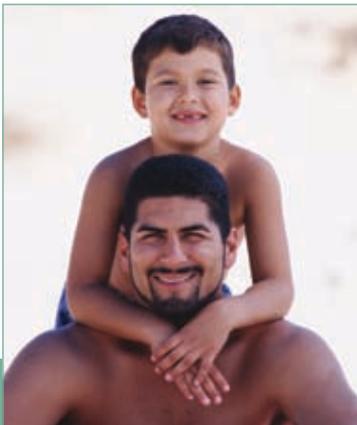
What is Muscular Dystrophy?

Muscular dystrophy is a group of disorders in which specific muscles of the body get weaker over time. Different kinds of muscular dystrophy affect people at different ages and affect different muscles. Duchenne/Becker Muscular Dystrophy (DBMD) is the most common muscular dystrophy in children. Some facts about DBMD include:

- DBMD affects about 1 out of every 3,500 to 6,000 boys. Girls rarely have DBMD.
- Of the more than 4 million births in the United States each year, about 400 to 600 are children who have DBMD.
- The Centers for Disease Control and Prevention (CDC) is working on a number of projects related to DBMD, including MD STAR_{net}.

For more information on DBMD projects at CDC, please visit:

www.cdc.gov/ncbddd/duchenne



What's happening in my state?

In Colorado, MD STAR_{net} is carried out through a partnership between The Children's Hospital and the Colorado Department of Public Health and Environment.

The Children's Hospital Muscle Clinic evaluates, diagnoses, and treats children and adolescents with neuromuscular diseases including Duchenne and Becker muscular dystrophy. The clinic staff includes specialists in:

- pediatric neurology
- pediatric rehabilitation medicine
- genetics
- physical therapy
- pulmonary rehabilitation
- social work
- rehabilitation nursing

In addition to providing specialized care, the neuromuscular clinic offers opportunities to participate in clinical trials. The clinic is partially funded through a grant from the Muscular Dystrophy Association.

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MD STAR_{net}

Following the Health of Individuals
with *Muscular Dystrophy*



What is MD STARnet?

MD STARnet, the Muscular Dystrophy Surveillance Tracking and Research Network, is a program set up in several states to identify all individuals who have DBMD.

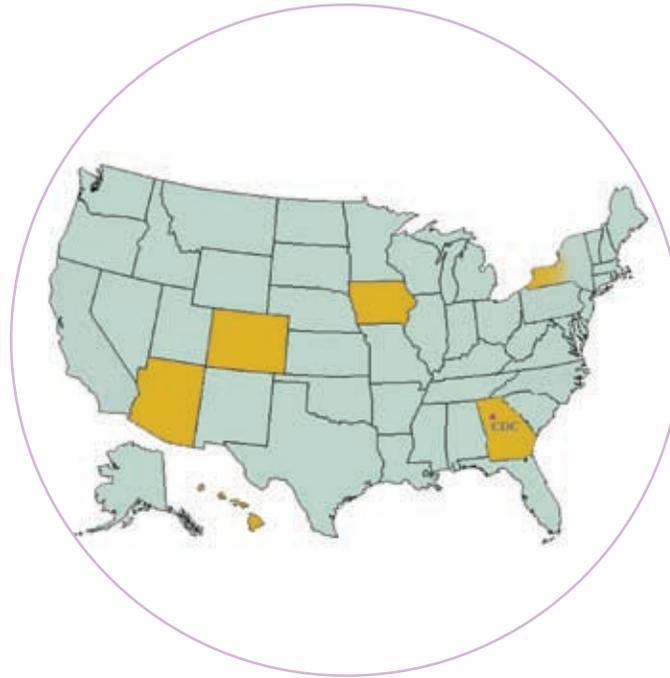
What is the purpose of MD STARnet?

The purpose of MD STARnet is to describe the health and service needs of individuals who have DBMD and their families. In addition, the program will enable us to better estimate the number of persons who have DBMD, which will then allow communities to provide better services, resources, and support. Ultimately, MD STARnet aims to improve the health and quality of life of all families affected by DBMD.



Who is involved in MDSTARnet?

Currently, six states make up the MD STARnet - Arizona, Colorado, Georgia, Hawaii, Iowa, and Western New York. The Centers for Disease Control and Prevention sponsors MD STARnet.



How does MD STARnet work?

Individuals who have DBMD are identified using information gathered from many different sources, such as clinic medical records and hospital records. Public health researchers collect information from these sources to keep track of each person's health care and changes over time. Researchers might ask families to take part in interviews and surveys to gather information related to DBMD that might not be found in the medical records.

All of the information about individuals who have DBMD are collected anonymously (without names) in order to answer questions such as:

- How common is DBMD?
- Is it equally common in different racial and ethnic groups?
- What are the early signs and symptoms of DBMD?
- Do things such as the type of care received or the type of gene changes affect the severity or course of DBMD?
- What health care-related services, medical and social, are families receiving?
- Does health care vary in different areas?
- Do different populations receive different care?



How
does
MD STARnet
work?