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. DBMD affects about 1 out of every 3,500 to 5,000 boys. Girls rarely have DBMD. Of the more than 4 million births in the United States each year, about 400 to 600 are children with DBMD. The Centers for Disease Control and Prevention is working on a number of projects related to DBMD, including MD STAR*net*.

MD STAR*net*

What's happening in my state?

In New York at the University of Rochester, the Neuromuscular Disease Clinic team is continuing to monitor the benefits and side effects of long-term prednisone treatment in a group of patients who have received prednisone since the mid 1980s. The goal is to develop a better understanding of the treatment regimen and offer an approach that maximizes benefits and minimizes side effects.

The group at the University of Rochester is looking at the effects of long-term prednisone therapy on:

- Prolonging independent walking;
- Development of scoliosis;
- Maintenance of pulmonary function; and
- Maintenance of cardiac function

For further information contact:

What *is* Muscular Dystrophy?

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CDC

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What is MD STAR*net*?

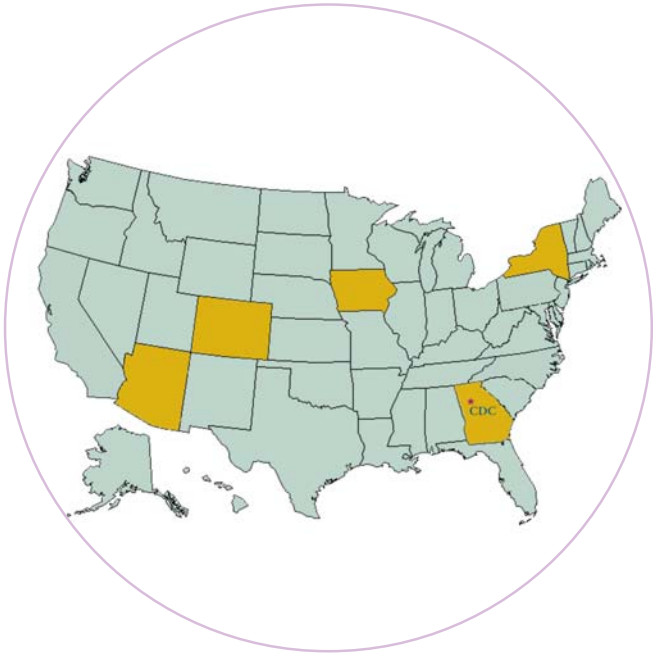
MD STAR*net*, the Muscular Dystrophy Surveillance Tracking and Research Network, is a program set up in several states to identify all children with DBMD.

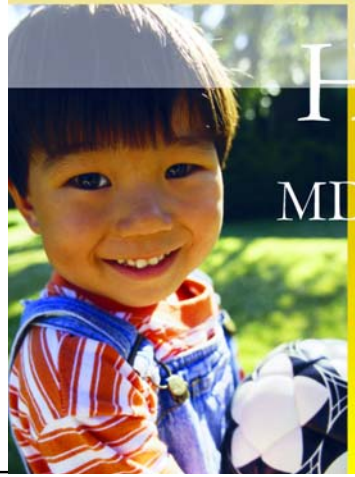
What are the expected benefits of MD STAR*net*?

Because MD STAR*net* is an ongoing activity, it will provide better estimates of the number of people with DBMD over time. It will describe the health and service needs of people with DBMD and their families, which in turn will allow communities to provide better services, resources, and support. Ultimately, MD STAR*net* aims to improve the health and quality of life of all families with DBMD.

Who is involved in MD STAR*net*?

Currently, CDC is working with Arizona, Colorado, Georgia, Iowa, and New York State on this project. Other states will be added as the project grows.





How does MD STAR*net* work?

Children with DBMD will be identified using information gathered from many different sources, such as clinic medical records and hospital records. Public health scientists will collect information from these sources to keep track of each child's health care and changes over time. Families will also be asked to take part in interviews with researchers to gather information related to DBMD that might not be found in the medical records.

All of the data collected will be pooled anonymously (without names) 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 factors 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?

www.cdc.gov/ncbddd

Department of Health and Human Services
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