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 Colorado, MD STAR*net* is being implemented through a partnership between The Children's Hospital and the Colorado Department of Public Health and Environment.

In addition to MD STAR*net*, the neuromuscular clinic team at The Children's Hospital is researching the use of Alendronate to treat osteoporosis in boys with Duchenne Muscular Dystrophy. Osteoporosis and bone fractures are common in boys with DMD as they get older and with steroid use. The goal is to determine if Alendronate, in conjunction with Vitamin D and calcium, will improve bone mineral density and reduce bone fractures in boys with Duchenne Muscular Dystrophy.

For further information contact:

Lisa Miller, MD, MSPH
Medical Director
Colorado Responds to Children with
Special Needs
Colorado Department of Public Health
and Environment
303-692-2700
lisa.miller@state.co.us

Dennis Matthews, MD
Chairman and Professor
Department of Rehabilitation Medicine
University of Colorado Health Sciences Center
The Children's Hospital
303-861-6633
matthews.dennis@tchden.org

What *is* Muscular Dystrophy?
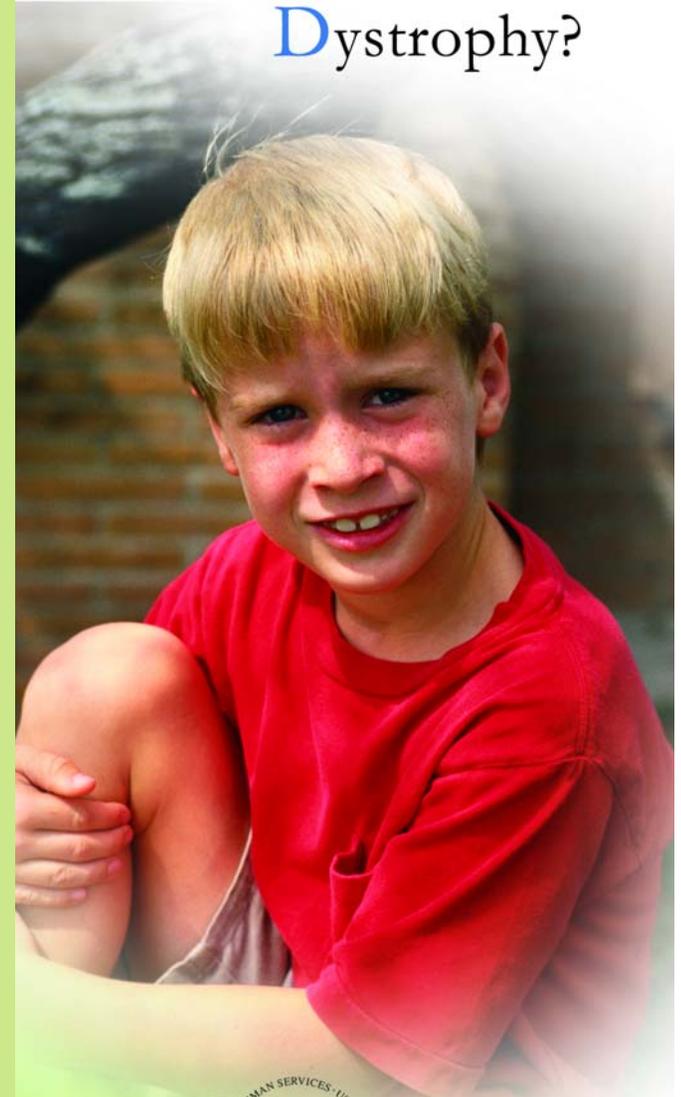
What is MD STAR*net*?

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.
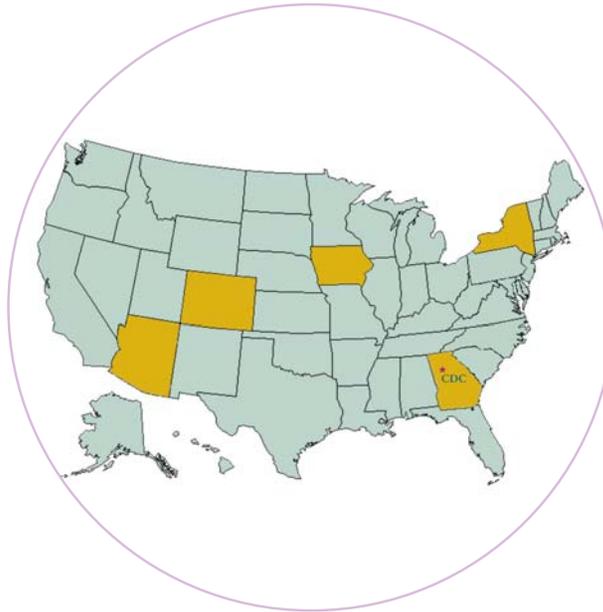
How does MD STAR*net* work?

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
Centers for Disease Control and Prevention

National Center on Birth Defects and
Developmental Disabilities
Atlanta, Georgia

How does MD STAR*net* work?