

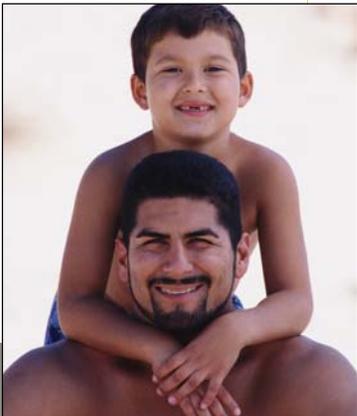
MD

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. 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 STARnet.

MD STARnet



MD STARnet Arizona is a joint venture of the Arizona University Center on Disabilities and the Section of Medical and Molecular Genetics in the Department of Pediatrics, University of Arizona College of Medicine.

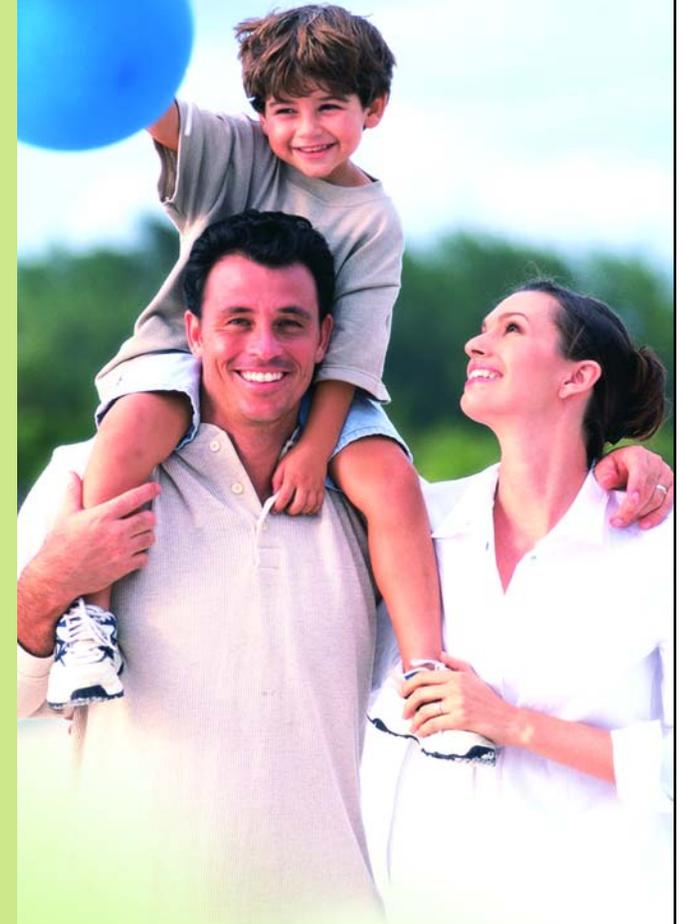
In addition to MD STARnet, Arizona faculty and staff are involved in a number of other projects related to muscular dystrophy. The following is a brief description of these projects.

- Palliative Care— Funded by the Association of University Centers on Disabilities, this project explores parents' understanding of palliative care issues and whether or not their needs are being met.
- Assistive Technology— This project, funded by the Muscular Dystrophy Association, assesses parent and child levels of satisfaction and knowledge of available devices used to promote independence and quality of life for persons with Duchenne and Becker Muscular Dystrophy.
- Genotyping— This is a program funded by the CDC to examine optimal strategies for genetic testing of persons with Duchenne and Becker Muscular Dystrophy, with an emphasis on informed consent and pretest and posttest counseling.

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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.

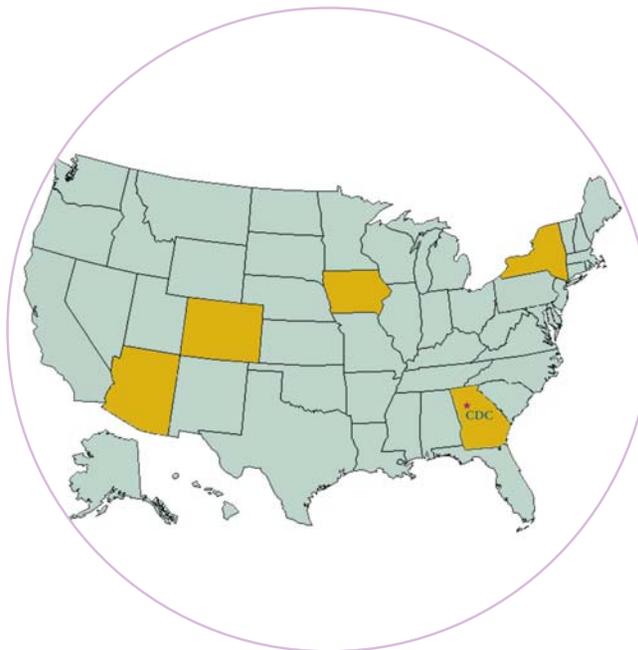
What are the expected benefits of MD STAR_{net}?

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 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?

www.cdc.gov/ncbddd

Department of Health and Human Services
Centers for Disease Control and Prevention

National Center on Birth Defects and
Developmental Disabilities
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