

## What is MD STARnet?

The Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) was established via funding from the Centers for Disease Control and Prevention in 2002, to learn more about various aspects of muscular dystrophies.

North Carolina became a MD STARnet site in 2014 when we were awarded a 5-year grant to collect data in the NC Piedmont region. The NC MD STARnet is a collaboration between RTI International and the University of North Carolina at Chapel Hill.

## Data Collection: Timing, Study Population, and Method

**Timing:** During 2015–2019, the North Carolina MD STARnet team is collecting baseline and longitudinal surveillance data on all individuals with MD that meet eligibility criteria.

**Study Population:** The MD STARnet sites collect data on individuals **with any** of the nine major types of muscular dystrophy (MD), which are:

1. Duchenne
2. Becker
3. Myotonic Dystrophy
4. Congenital
5. Limb Girdle
6. Emery-Dreifuss
7. Facioscapulohumeral
8. Distal
9. Oculopharyngeal

Each of these muscular dystrophies vary by age of onset, muscle groups affected, genes involved, severity, and disease progression.

**Method:** North Carolina MD STARnet conducts longitudinal surveillance of muscular dystrophy under a Grant of Authority from the North Carolina Department of Health and Human Services. The grant of authority allows us to conduct public health surveillance under the State’s public health authority. Public health surveillance does not require consent from the patient and or their parent/guardian.

North Carolina MD STARnet began collecting baseline data for individuals with Duchenne and Becker MD (DBMD) in October 2015 and will collect follow-up data annually until the study ends. As we complete baseline data collection for DBMD, we will begin baseline collection on other MDs such as myotonic dystrophy and limb girdle muscular dystrophy. This means that each year baseline and follow-up data will be collected on multiple types of MD.

Individuals with MD are ascertained from medical records or administrative datasets, such as state hospital discharge data. An NC MD STARnet abstractor reviews the medical records of each ascertained individual to evaluate their eligibility, and abstracts data for eligible individuals. All data is coded with a unique ID to protect the patient’s privacy and confidentiality.

Baseline abstraction requires a comprehensive review of patients’ medical records, in each participating healthcare system and provider from the start of the cohort eligibility period until the first abstraction. For Duchenne, Becker, and congenital muscular dystrophy, eligibility begins at birth and the cohort includes all individuals born on January 1, 2000, or later. For other muscular dystrophies, individuals of all ages are eligible, but the cohort only includes information on healthcare visits on or after January 1, 2008. We will collect information from records for healthcare visits through December 31, 2018. Hence, baseline abstraction may include many years of data. Follow-up abstraction consists of a comprehensive review of the record since the last abstraction.

## What are the current objectives of MD STARnet?

For the current 2014–2019 funding cycle, the MD STARnet sites will:

- Revise the pilot surveillance protocol for all MDs,
- Conduct longitudinal surveillance for all MDs,
- Provide information on the prevalence and clinical attributes of muscular dystrophy in minority racial and ethnic populations,
- Pilot surveillance of other neuromuscular disorders, and
- Examine potential of surveillance following newborn screening.

## What is the North Carolina MD STARnet site's catchment area?

The catchment area for the NC MD STARnet site is the Piedmont region of North Carolina. This region includes the central portion of North Carolina, encompasses its largest urban areas, and is where more than 50% of the state's residents live. One of North Carolina's contributions to muscular dystrophy surveillance is our diverse population, which is 22% African American within the Piedmont region. The high percentage of African Americans will enable the NC MD STARnet site to provide key information for the MD STARnet objective of providing information on the prevalence and clinical attributes of MD in minority racial and ethnic populations.

## Why is MD STARnet important?

MD STARnet is the only research program designed to monitor and collect data on everyone with MD who live in specific areas of the United States. By collecting data on everyone, the MD STARnet program yields broader evidence based research to help improve the care and quality of life for those living with MD.

The goal is for MD STARnet to be the most comprehensive source of data on muscular dystrophy nationwide. This data provides researchers a standard comprehensive dataset to conduct research on a variety of public health issues such as delay in diagnosis, variations in care, and the impact of MD on families and caregivers.

## What states are involved?

MD STARnet consists of 3 legacy sites (Iowa, Colorado, and New York) and 3 new sites which joined during the 2014–2019 grant cycle (North Carolina, South Carolina, and Utah/Nevada).

## Who supports and advises NC MD STARnet?

Each site has various partners/supporters. North Carolina partners and supporters include: the North Carolina Division of Public Health, the North Carolina Neurological Society, the North Carolina Pediatric Society, and local and national muscular dystrophy organizations, including the Muscular Dystrophy Association, the Myotonic Dystrophy Foundation, the Parent Project Muscular Dystrophy, and the Facioscapulohumeral MD Society.

## Where are the NC MD STARnet data collection sites?

Our data collection sites include the four Muscular Dystrophy Association clinics within the state: Carolinas Medical Center, University of North Carolina at Chapel Hill, Duke University Medical Center, and Wake Forest University Baptist Medical Center. **These sites are vital to the success of the MD STARnet activities through** providing on-going access to comprehensive information on individuals with MD. Examples of this information are: records from clinic visits, hospitalizations, ER visits, and utilization of allied healthcare services (like physical, psychological, and occupational therapy). We will also collect information at private neurologists' offices and at hospitals or other healthcare facilities as needed.

## Questions:

The best way to contact the NC MD STARnet team is via e-mail at [mdstarnetnorthcarolina@rti.org](mailto:mdstarnetnorthcarolina@rti.org)

To learn more about MD STARnet in general, please visit the CDC's site on the surveillance system:

<http://www.cdc.gov/ncbddd/muscular dystrophy/research.html>