

A photograph of a woman with short dark hair, wearing a light green jacket, hugging a young boy from behind. The boy is sitting in a wheelchair and is wearing a light-colored sweater and blue jeans. Both are smiling warmly. The background is a soft, light blue gradient.

MD STARnet

What is MD STARnet?

The Muscular Dystrophy Surveillance, Tracking and Research Network (MD STARnet) is a data collection and research program that analyzes information provided by individuals with muscular dystrophy (MD). Funded by the U.S. Centers for Disease Control and Prevention (CDC), 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. Most MD research programs collect data only on people with the disease who are treated by specialists at certain medical clinics. 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 MD nationwide.

Why is MD STARnet being conducted in the Piedmont region of North Carolina?

In September 2014, North Carolina was added to the MD STARnet project as one of three new states for which information on individuals living with MD will be collected. The Piedmont region is the largest urban area in North Carolina, home to more than half of the state's residents, and the location for all four of the state's Muscular Dystrophy Association clinics and a Parent Project Muscular Dystrophy Certified Duchenne Care Center.

In addition, examining racial disparities is a high priority for MD STARnet and the Piedmont region will be one of the first sites with a substantial representation of African Americans. The region's rich cultural and racial diversity will provide vital information that helps health care providers, researchers, and African American families living with MD better understand the prevalence and course of MD among African Americans.

Who is conducting the MD STARnet Surveillance System in the Piedmont area?

RTI International is working together with the University of North Carolina Chapel Hill (UNC-CH). In the fall of 2014, the RTI-UNC-CH team was awarded a cooperative agreement with CDC to conduct MD STARnet in North Carolina.



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Where can I learn more about MD STARnet?

To learn more about North Carolina's surveillance system, visit: mdstarnetnorthcarolina.rti.org

To learn more about CDC's Muscular Dystrophy Surveillance, Tracking, and Research Network, visit: <http://www.cdc.gov/ncbddd/muscular dystrophy/research.html>

For questions and more information about the MD STARnet Piedmont, North Carolina project, please email mdstarnetnorthcarolina@rti.org

Does the project have Institutional Review Board (IRB) Approval?

The project was reviewed by RTI and UNC-CH IRBs and determined to be public health practice, not research.

What are the benefits of MD STARnet for providers?

- Findings from MD STARnet are reliable and can paint a more complete picture of MD for providers, researchers, policymakers, and partners.
- Findings from MD STARnet can help you better treat patients with MD.
- Findings from MD STARnet encourage standardization of care across all health professions that treat patients with MD.

How can area providers support MD STARnet in the Piedmont region?

If you treat patients with muscular dystrophy,

- let us know,
- help us with accessing your patients' medical records, and
- inform your patients with muscular dystrophy about the project.

What is MD STARnet?

Who are MD STARnet partners in North Carolina?

The MD STARnet Surveillance System is seen as a valuable program for individuals living with MD, their families, health care providers, researchers, policymakers, and MD organizations in North Carolina. Among MD STARnet's partners and supporters are the North Carolina Division of Public Health, the North Carolina Neurological Society, the North Carolina Pediatric Society, and local and national MD organizations, including the Muscular Dystrophy Association, the Myotonic Dystrophy Foundation, the Parent Project Muscular Dystrophy, and the Facioscapulohumeral MD Society.