



Muscular Dystrophy in the North Carolina Piedmont Duchenne and Becker Muscular Dystrophy

What are Duchenne and Becker Muscular Dystrophies?

Duchenne and Becker muscular dystrophies (DBMD) are genetic disorders of muscle function caused by changes in the dystrophin gene, which is on the X-chromosome. In almost all cases, people with DBMD are boys or men. They either inherit the disease from their asymptomatic (or very mildly affected) mother or have a new change in the dystrophin gene. Approximately one-third of people affected by DBMD have new mutations.

People with DBMD have progressive muscle atrophy and weakness of their muscles, including the heart. Duchenne muscular dystrophy (DMD) is the more severe form of the disease. Boys with DMD have noticeable muscle weakness by early childhood. They may be slow to sit or walk, or have problems learning to speak. Most boys with DMD require a wheelchair by their early teens. Breathing problems and progressive heart weakness may be life-threatening. Becker muscular dystrophy (BMD) is milder than DMD, with a wider range of severity. Boys with BMD usually develop muscle weakness in later childhood or adolescence and have much slower progression. They also exhibit heart problems, usually beginning in adolescence. Individuals with DMD usually live into their twenties, while those with BMD live into their forties or later.

Additional information about DBMD can be found on the following websites:

[Parent Project Muscular Dystrophy](#) [The Genetics Home Reference](#) [Muscular Dystrophy Association](#)
[Centers for Disease Control and Prevention](#)

How Many People Have Duchenne and Becker Muscular Dystrophy in the Piedmont Region of North Carolina?

We identified 71 individuals within our study area who were born in the year 2000 or later and diagnosed with Duchenne or Becker muscular dystrophy before December 31, 2015. An additional six individuals had a positive genetic test without current symptoms of the disease (asymptomatic). We study muscular dystrophy in 33 counties in the central region of North Carolina. On January 1, 2019, their average age was 14 years (standard deviation, 3.4 years). The following charts show the characteristics of people living with DBMD in North Carolina.

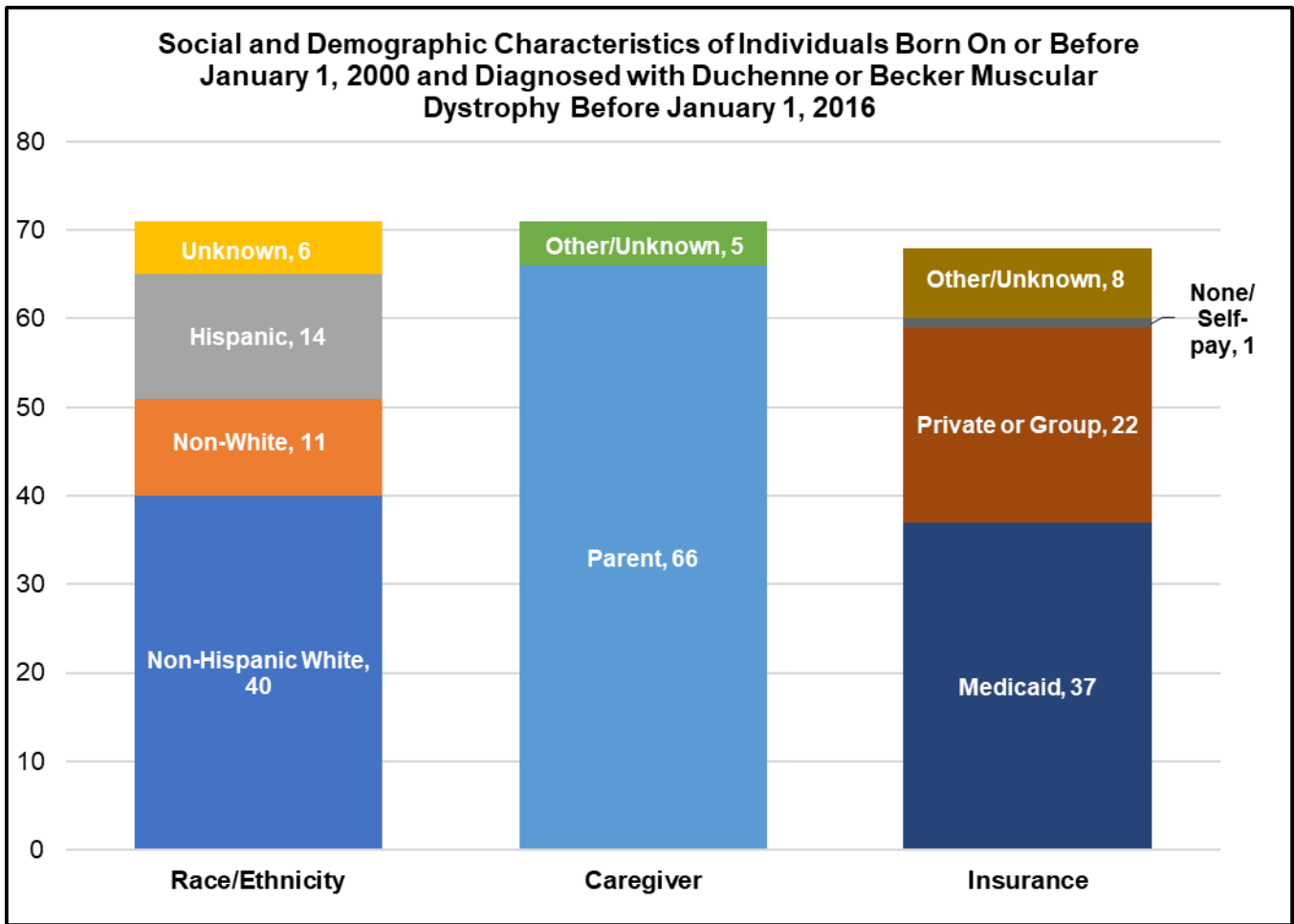


Chart 1. Social and demographic characteristics of individuals born in 2000 or later who were diagnosed with Duchenne and Becker muscular dystrophy before January 1, 2016

What Are Their Clinical Characteristics and What Clinical Care Have They Received?

The 71 diagnosed individuals we identified were confirmed to have DBMD by genetic testing in themselves or a family member (definite). On average, people with DBMD first showed symptoms of the disease at age 3.7 years and were diagnosed at age 5.0 years. Boys with DMD lost the ability to walk at an average of 10.2 years. Boys with DBMD are typically prescribed corticosteroids to reduce the incidence of cardiomyopathy and prolong their ability to walk.

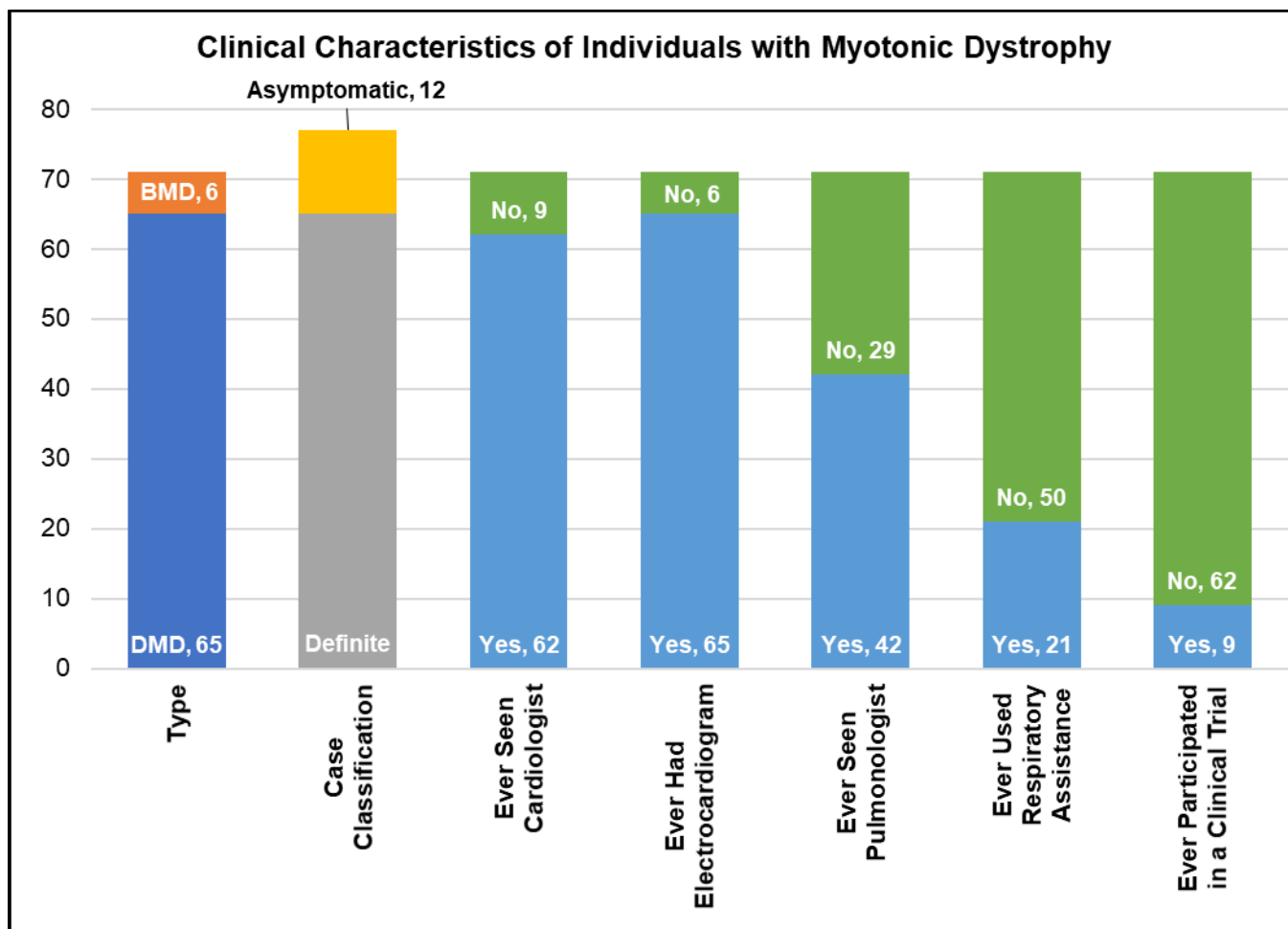


Chart 2. Clinical characteristics of individuals born in 2000 or later who were diagnosed with Duchenne and Becker muscular dystrophy before January 1, 2016

How Did We Get These Numbers?

The Muscular Dystrophy Surveillance, Tracking, and Research Network (MD STARnet) is a public health surveillance program designed to collect health information on everyone with muscular dystrophies living in specific areas of the United States. MD STARnet identifies individuals with muscular dystrophy from medical records at neuromuscular clinics and other places they seek care. MD STARnet is funded and managed by the Centers for Disease Control and Prevention and comprises researchers at state departments of health, universities, and nonprofit research institutes. Each project is either reviewed and approved by Institutional Review Boards or authorized by the public health authority in the state in which the surveillance is conducted. North Carolina joined MD STARnet in 2014. We collect data about individuals with muscular dystrophies who live in any of the 33 counties in the central, Piedmont region of the state: Alamance, Anson, Cabarrus, Caswell, Chatham, Davidson, Davie, Durham, Forsyth, Franklin, Gaston, Granville, Guilford, Iredell, Lee, Lincoln, Mecklenburg, Montgomery, Moore, Orange, Person, Randolph, Richmond, Rockingham, Rowan, Stanly, Stokes, Surry, Union, Vance, Wake, Warren, and Yadkin Counties.