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Researchers report new figures on two muscular dystrophy disorders

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Researchers in public health have reported in the first broad study in the United States the frequency of two muscle-weakness disorders that strike mostly boys: Duchenne muscular dystrophy and Becker muscular dystrophy.

The research team, led by the University of Iowa, found that about 1 in 5,000 boys, between 5 and 9 years old, have the inherited disorders. They also find the diseases appear to affect Hispanic boys more often than white or African-American boys, for reasons that are not well understood.

The findings are important, because they give a better understanding of the number of children and families affected by the disorders. They also give doctors and health-care professionals valuable information, so they can better plan to care for those affected, especially as the diseases progress.

"There were always some rather crude estimates of how common these muscular dystrophies are," says Paul Romitti, an epidemiologist at the UI and corresponding author of the study, published online in the journal *Pediatrics*. "It tells us that they're still an important public health concern."

Muscular dystrophies are a group of genetic disorders that result in muscle weakness over time. The most common muscular dystrophy in children is Duchenne muscular dystrophy, which predominantly affects

males. Historically, Duchenne has resulted in loss of walking ability between ages 7 and 13 years, and death in the teens or 20s. Becker muscular dystrophy is similar to Duchenne, but has later onset and slower, more variable progression of symptoms. There is no cure for either disorder.

In the population-based study, researchers analyzed data - culled mostly from birth and death certificates and medical records - for children born between 1982 and 2011 in six states: Arizona, Colorado, Georgia, Hawaii, Iowa and western New York. They calculated the disorders' prevalence across four five-year time periods, beginning in the 1991-1995 period and ending in 2006-2010.

The U.S. Centers for Disease Control funded the work, through the Muscular Dystrophy Surveillance, Research and Tracking Network, or MD STARnet.

The team found the disorders in roughly 2 per 10,000 boys in the 1991-1995, 1996-2000 and 2001-2005 periods. In 2006-2010, the prevalence was 1.5, but the researchers believe the lower figure could be due to delayed diagnosis, among other factors.

Hispanic youth had a higher prevalence in all but the last time period, while African-American children were least likely to be affected for all time periods.

Three-quarters of the 845 total cases were Duchenne, according to the study.

The frequency across the time periods is roughly the same as found in a MD STARnet study, in four states and reported in 2007, and from a study done in Colorado in 1974, according to the paper.

Despite their rarity, the researchers say medical professionals should be prepared.

"People who have these disorders require daily attention from their families and complex-care management from health-care providers," says Romitti, professor in the UI College of Public Health. "The new data will help to estimate the cost for the parents and the health-care system. We are continuing to learn more about the total impact of these disorders on the child and the family."

Provided by University of Iowa