



**Ohio Life Sciences  
Testimony in Support of HC0021  
Finance Subcommittee on Health and Human Services**

Chairwoman Carruthers, Ranking Member Liston, and Members of the Finance Subcommittee on Health and Human Services, thank you for the opportunity to provide written testimony in support of HC0021, a budget amendment adding Duchenne Muscular Dystrophy (DMD) to the state's newborn screening panel.

My name is Willa Bluestone and I serve as the Director of Policy and Workforce at Ohio Life Sciences. We are the trade association for all of the life science organizations, companies, and researchers within Ohio. Our member organizations include pharmaceutical researchers and developers, medical device manufacturers, gene and cell therapy institutions, and many others. Our member organizations represent the absolute cutting edge of medical research. Each day, new developments are made that enable Ohioans to live happier and healthier lives.

As many of you know, The Ohio Department of Health oversees a program to identify newborn babies who are at risk of rare medical conditions that will significantly impact life span or quality of life.

Ohio law requires all newborns to be screened for a variety of serious medical conditions within the first 5 days of birth. The newborn screening panel only requires a few drops of blood from the baby's heel to test for almost *40 separate health conditions*. Typically, and thankfully, most newborn screening test results are normal. However, there are some babies who are not so lucky. Of the approximately 3,000 babies that receive abnormal results, less than 10% of them will receive a diagnosis that requires medical intervention. With such early diagnosis and testing, serious health problems, including death, are prevented.

This budget amendment (HB0021), would add Duchenne Muscular Dystrophy (DMD) to the newborn screening panel. DMD is a form of muscular dystrophy that worsens significantly quicker than others. DMD most often affect boys, occurring in about 1/3,600 male infants making it one of the most common fatal genetic disorders.

The average age of diagnosis for Duchenne Muscular Dystrophy is 5 years old. **This means, on average, a child diagnosed with DMD will have already suffered through 5 years' worth of muscular degeneration before doctor's are able to identify the cause.** The muscles are not stagnating once the child is born or even developing at a slower rate than normal – they are *actively degenerating*. As a result, children are faced with irreversible muscle damage all before they start first grade. As expected, a greater delay in diagnosis is seen in families of color and those from a low socioeconomic class.

By adding DMD to the newborn screening panel, we decrease the number of unnecessary, costly, and painful tests. We decrease the amount of time that parents spend worrying about an unknown illness wreaking havoc on their child's body. **We increase the ability for families to make proactive decisions that will drastically improve their child's quality of life.**



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The Department of Health website states, “The overall goal of the NBS [newborn screening] program is to improve the quality of life for babies through early diagnosis and treatment. Time is a very important element in this process. Cooperation and timely action by parents and medical providers will help all babies get a healthy start at life.” Adding Duchenne Muscular Dystrophy to the newborn screening panel works towards the Department of Health’s vision for this program.

Ohio Life Sciences is supportive of budget amendment HC0021 and welcomes any questions that may arise as a result of this written testimony. Thank you for the opportunity to provide testimony.

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