



H.R. 5265 – Paul D. Wellstone Muscular Dystrophy Community Assistance, Research, and Education Amendments of 2008, as amended

FLOOR SITUATION

H.R. 5265 is being considered on the floor under suspension of the rules and will require a two-thirds majority vote for passage. This legislation was introduced by Representative Eliot Engel (D-NY) on February 7, 2008. The House passed the bill on September 24, 2006, by a vote of 418-2. The Senate passed H.R. 5265 with an amendment on September 26, 2008, by unanimous consent.

Note: The Senate amended this bill to make technical corrections and mandate a CDC report to Congress on September 26, 2008.

H.R. 5265 is expected to be considered on the floor of the House on September 27, 2008.

SUMMARY

H.R. 5265 designates centers of excellence for research on various forms of muscular dystrophy as the Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers and requires the Muscular Dystrophy Interagency Coordinating Committee to give consideration to enhancing clinical research infrastructure required to test emerging therapies for muscular dystrophy.

The bill directs the Secretary of Health and Human Services to ensure that data on patients that is collected as part of the Muscular Dystrophy Surveillance, Tracking and Research Network (MD STARnet) is updated to reflect changes in patient condition over time. The Director of the Centers for Disease Control and Prevention (CDC) must report to Congress on MD STARnet and data collection, as well as provide outcome data on the health and survival of people with muscular dystrophy. The CDC Director also must provide information and education on muscular dystrophy to health professionals and the general public and widely disseminate the Duchenne-Becker muscular dystrophy care considerations.

H.R. 5265 requires the CDC Director to report to Congress within 18 months on the MD STARnet site.

BACKGROUND

Muscular dystrophy is a group of genetic diseases which cause progressive muscle weakness. The best-known type of muscular dystrophy is Duchenne muscular dystrophy (DMD). Other forms of the disease include Myotonic muscular dystrophy and congenital muscular dystrophy. Frequent symptoms of muscular dystrophy include muscle weakness, respiratory difficulty, inability to walk, and poor balance. There is no known cure or any specific treatments for muscular dystrophy.

On December 18, 2001 the MD CARE Act was signed into law by President Bush. This legislation amended the Public Health Service Act to provide research for the various muscular dystrophies. The MD CARE Act also established the Muscular Dystrophy Coordinating Committee to help focus research efforts through a coherent research strategy.

COST

The Congressional Budget Office (CBO) has not produced a cost estimate for H.R. 5265 as of September 27, 2008.

STAFF CONTACT

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LEGISLATIVE DIGEST

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