



H.R. 2295 – ALS Registry Act

FLOOR SITUATION

H.R. 2295 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 May 14, 2007.

H.R. 2295 is expected to be considered on the House floor on October 15, 2007.

SUMMARY

H.R. 2295 establishes the Amyotrophic Lateral Sclerosis (ALS) Registry at the Centers for Disease Control and Prevention. The registry would gather data on the incidence and prevalence of ALS in the United States and possible genetic, environmental, and occupational factors associated with ALS.

This legislation authorizes \$25 million for fiscal year 2008, and such sums as necessary for each of fiscal years 2009-2012.

BACKGROUND

ALS is a fatal, progressive neurodegenerative disease that affects motor nerve cells in the brain and spinal cord. The cause of ALS is not well understood, and there is no known cure for the disease.

More than 5,000 individuals in the United States are diagnosed with ALS each year.

There are currently several ALS disease registries and databases in the United States, including the SOD1 database, the National Institute of Neurological Disorders and Stroke Repository, and the Department of Veterans Affairs ALS Registry.

In 2006 and 2007, Congress appropriated \$887,000 to the CDC to begin a nationwide ALS registry.

COST

Based on historical patterns of spending for similar activities, the Congressional Budget Office (CBO) estimates that implementing H.R. 2295 would cost \$10 million in 2008 and \$75 million over 2008-2012.

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