

S 1353

ALS Registry Act

Congress: 109 (2005–2007, Ended)

Chamber: Senate

Policy Area: Health

Introduced: Jun 30, 2005

Current Status: Read twice and referred to the Committee on Health, Education, Labor, and Pensions. (text of measure

Latest Action: Read twice and referred to the Committee on Health, Education, Labor, and Pensions. (text of measure as introduced: CR 7/1/2005 S7836-7837) (Jun 30, 2005)

Official Text: <https://www.congress.gov/bill/109th-congress/senate-bill/1353>

Sponsor

Name: Sen. Reid, Harry [D-NV]

Party: Democratic • **State:** NV • **Chamber:** Senate

Cosponsors (50 total)

Cosponsor	Party / State	Role	Date Joined
Sen. Bingaman, Jeff [D-NM]	D · NM		Jun 30, 2005
Sen. Cochran, Thad [R-MS]	R · MS		Jun 30, 2005
Sen. Corzine, Jon S. [D-NJ]	D · NJ		Jun 30, 2005
Sen. Durbin, Richard J. [D-IL]	D · IL		Jun 30, 2005
Sen. Murkowski, Lisa [R-AK]	R · AK		Jun 30, 2005
Sen. Stabenow, Debbie [D-MI]	D · MI		Jun 30, 2005
Sen. Vitter, David [R-LA]	R · LA		Jun 30, 2005
Sen. Warner, John [R-VA]	R · VA		Jun 30, 2005
Sen. Smith, Gordon H. [R-OR]	R · OR		Jul 11, 2005
Sen. Landrieu, Mary L. [D-LA]	D · LA		Jul 14, 2005
Sen. Lautenberg, Frank R. [D-NJ]	D · NJ		Jul 18, 2005
Sen. Nelson, Ben [D-NE]	D · NE		Jul 28, 2005
Sen. Boxer, Barbara [D-CA]	D · CA		Oct 17, 2005
Sen. Bayh, Evan [D-IN]	D · IN		Oct 19, 2005
Sen. Nelson, Bill [D-FL]	D · FL		Oct 24, 2005
Sen. Dayton, Mark [D-MN]	D · MN		Dec 12, 2005
Sen. Dodd, Christopher J. [D-CT]	D · CT		Jan 25, 2006
Sen. Murray, Patty [D-WA]	D · WA		May 15, 2006
Sen. Akaka, Daniel K. [D-HI]	D · HI		May 17, 2006
Sen. Craig, Larry E. [R-ID]	R · ID		May 17, 2006
Sen. Inouye, Daniel K. [D-HI]	D · HI		May 18, 2006
Sen. Menendez, Robert [D-NJ]	D · NJ		May 18, 2006
Sen. Allen, George [R-VA]	R · VA		May 22, 2006
Sen. Burr, Richard [R-NC]	R · NC		May 22, 2006
Sen. Martinez, Mel [R-FL]	R · FL		May 22, 2006
Sen. Burns, Conrad R. [R-MT]	R · MT		May 23, 2006
Sen. Coleman, Norm [R-MN]	R · MN		May 23, 2006
Sen. DeWine, Mike [R-OH]	R · OH		May 25, 2006
Sen. Feinstein, Dianne [D-CA]	D · CA		May 25, 2006
Sen. Graham, Lindsey [R-SC]	R · SC		May 25, 2006
Sen. Bunning, Jim [R-KY]	R · KY		Jun 7, 2006
Sen. Dorgan, Byron L. [D-ND]	D · ND		Jun 7, 2006
Sen. Lieberman, Joseph I. [D-CT]	D · CT		Jun 7, 2006
Sen. Kennedy, Edward M. [D-MA]	D · MA		Jun 8, 2006
Sen. Dole, Elizabeth [R-NC]	R · NC		Jun 12, 2006
Sen. Sessions, Jeff [R-AL]	R · AL		Jun 15, 2006
Sen. Conrad, Kent [D-ND]	D · ND		Jun 16, 2006
Sen. Lincoln, Blanche L. [D-AR]	D · AR		Jun 23, 2006
Sen. Santorum, Rick [R-PA]	R · PA		Jun 27, 2006
Sen. Carper, Thomas R. [D-DE]	D · DE		Jun 28, 2006
Sen. Pryor, Mark L. [D-AR]	D · AR		Jun 29, 2006

Cosponsor	Party / State	Role	Date Joined
Sen. DeMint, Jim [R-SC]	R · SC		Jul 13, 2006
Sen. Baucus, Max [D-MT]	D · MT		Sep 5, 2006
Sen. Clinton, Hillary Rodham [D-NY]	D · NY		Sep 5, 2006
Sen. Schumer, Charles E. [D-NY]	D · NY		Sep 5, 2006
Sen. Kerry, John F. [D-MA]	D · MA		Sep 26, 2006
Sen. Talent, Jim [R-MO]	R · MO		Sep 29, 2006
Sen. Wyden, Ron [D-OR]	D · OR		Sep 29, 2006
Sen. Collins, Susan M. [R-ME]	R · ME		Nov 13, 2006
Sen. Levin, Carl [D-MI]	D · MI		Nov 13, 2006

Committee Activity

Committee	Chamber	Activity	Date
Health, Education, Labor, and Pensions Committee	Senate	Referred To	Jun 30, 2005

Subjects & Policy Tags

Policy Area:

Health

Related Bills

Bill	Relationship	Last Action
109 HR 4033	Identical bill	Oct 17, 2005: Referred to the Subcommittee on Health.

Summary (as of Jun 30, 2005)

ALS Registry Act - Amends the Public Health Service Act to require the Secretary of Health and Human Services, acting through the Director of the Centers for Disease Control and Prevention (CDC), to: (1) develop a system to collect data on amyotrophic lateral sclerosis (ALS); and (2) establish a national registry for the collection and storage of ALS data.

Requires the Secretary, acting through the Director, to establish the Advisory Committee on the National ALS Registry to study and make recommendations to the Secretary concerning: (1) the development and maintenance of the registry; (2) the type of information to be included; (3) the manner in which data is to be collected; (4) the use and availability of such data; and (5) the collection of information about diseases and disorders that primarily affect motor neurons that are considered essential to furthering the study and cure of ALS.

Allows the Secretary, acting through the Director, to award grants to, and enter into contracts and cooperative agreements with, public or private nonprofit entities for the collection, analysis, and reporting of data on ALS.

Requires the Secretary, acting through the Director, to: (1) identify, build upon, expand, and coordinate among existing data and surveillance systems, surveys, registries, and other federal public health and environmental infrastructure wherever possible; and (2) provide for public access to an electronic national database that accepts data from state registries, health care professionals, and others as recommended by the Advisory Committee in a manner that protects personal privacy.

Requires the Secretary to ensure that epidemiological and other types of information is made available to the National Institutes of Health (NIH) and the Department of Veterans Affairs.

Actions Timeline

- **Jun 30, 2005:** Introduced in Senate
- **Jun 30, 2005:** Sponsor introductory remarks on measure. (CR 7/1/2005 S7836)
- **Jun 30, 2005:** Read twice and referred to the Committee on Health, Education, Labor, and Pensions. (text of measure as introduced: CR 7/1/2005 S7836-7837)