

## HR 4033

ALS Registry Act

**Congress:** 109 (2005–2007, Ended)

**Chamber:** House

**Policy Area:** Health

**Introduced:** Oct 7, 2005

**Current Status:** Referred to the Subcommittee on Health.

**Latest Action:** Referred to the Subcommittee on Health. (Oct 17, 2005)

**Official Text:** <https://www.congress.gov/bill/109th-congress/house-bill/4033>

### Sponsor

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**Name:** Rep. Engel, Eliot L. [D-NY-17]

**Party:** Democratic • **State:** NY • **Chamber:** House

**Cosponsors** (215 total)

<b>Cosponsor</b>	<b>Party / State</b>	<b>Role</b>	<b>Date Joined</b>
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Rep. Goode, Virgil H., Jr. [R-VA-5]	R · VA		Oct 7, 2005
Rep. Grijalva, Raúl M. [D-AZ-7]	D · AZ		Oct 7, 2005
Rep. Higgins, Brian [D-NY-27]	D · NY		Oct 7, 2005
Rep. Hinchey, Maurice D. [D-NY-22]	D · NY		Oct 7, 2005
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Rep. Sanders, Bernard [I-VT-At Large]	I · VT		Oct 7, 2005
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Rep. Scott, David [D-GA-13]	D · GA		Oct 7, 2005
Rep. Shays, Christopher [R-CT-4]	R · CT		Oct 7, 2005
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Rep. Terry, Lee [R-NE-2]	R · NE		Oct 7, 2005
Rep. Towns, Edolphus [D-NY-10]	D · NY		Oct 7, 2005
Rep. Van Hollen, Chris [D-MD-8]	D · MD		Oct 7, 2005

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Rep. Wasserman Schultz, Debbie [D-FL-20]	D · FL		Oct 7, 2005
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Rep. Whitfield, Ed [R-KY-1]	R · KY		Oct 7, 2005
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Rep. Saxton, Jim [R-NJ-3]	R · NJ		Oct 17, 2005
Rep. Stearns, Cliff [R-FL-6]	R · FL		Oct 17, 2005
Rep. Upton, Fred [R-MI-6]	R · MI		Oct 17, 2005
Rep. Boehlert, Sherwood [R-NY-24]	R · NY		Oct 18, 2005
Rep. Udall, Mark [D-CO-2]	D · CO		Oct 18, 2005
Rep. Davis, Susan A. [D-CA-53]	D · CA		Oct 20, 2005
Rep. Norwood, Charles W. [R-GA-9]	R · GA		Oct 20, 2005
Rep. Cramer, Robert E. (Bud), Jr. [D-AL-5]	D · AL		Oct 28, 2005
Rep. Case, Ed [D-HI-2]	D · HI		Nov 1, 2005
Rep. Skelton, Ike [D-MO-4]	D · MO		Nov 3, 2005
Rep. Baldwin, Tammy [D-WI-2]	D · WI		Nov 7, 2005
Rep. Weldon, Dave [R-FL-15]	R · FL		Nov 7, 2005
Rep. Evans, Lane [D-IL-17]	D · IL		Nov 17, 2005
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Rep. Pallone, Frank, Jr. [D-NJ-6]	D · NJ		Dec 14, 2005
Rep. Tiberi, Patrick J. [R-OH-12]	R · OH		Dec 15, 2005
Rep. Kelly, Sue W. [R-NY-19]	R · NY		Dec 22, 2005
Rep. Frank, Barney [D-MA-4]	D · MA		Feb 8, 2006
Rep. Sanchez, Loretta [D-CA-47]	D · CA		Feb 8, 2006
Rep. Barrow, John [D-GA-12]	D · GA		Feb 14, 2006
Rep. McGovern, James P. [D-MA-3]	D · MA		Feb 14, 2006
Rep. Fitzpatrick, Michael G. [R-PA-8]	R · PA		Mar 9, 2006
Rep. Gallegly, Elton [R-CA-24]	R · CA		Mar 9, 2006
Rep. Honda, Michael M. [D-CA-15]	D · CA		Mar 9, 2006
Rep. Markey, Edward J. [D-MA-7]	D · MA		Mar 28, 2006
Rep. Melancon, Charlie [D-LA-3]	D · LA		Mar 28, 2006
Rep. Castle, Michael N. [R-DE-At Large]	R · DE		Apr 6, 2006
Rep. Blumenauer, Earl [D-OR-3]	D · OR		Apr 27, 2006
Rep. Chabot, Steve [R-OH-1]	R · OH		Apr 27, 2006
Rep. Larson, John B. [D-CT-1]	D · CT		May 11, 2006
Rep. Bishop, Timothy H. [D-NY-1]	D · NY		May 18, 2006
Rep. Boswell, Leonard L. [D-IA-3]	D · IA		May 18, 2006
Rep. Brown, Corrine [D-FL-3]	D · FL		May 18, 2006

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Rep. Davis, Artur [D-AL-7]	D · AL		May 18, 2006
Rep. Davis, Jo Ann [R-VA-1]	R · VA		May 18, 2006
Rep. Davis, Tom [R-VA-11]	R · VA		May 18, 2006
Rep. Farr, Sam [D-CA-17]	D · CA		May 18, 2006
Rep. Ford, Harold E., Jr. [D-TN-9]	D · TN		May 18, 2006
Rep. Hayworth, J. D. [R-AZ-5]	R · AZ		May 18, 2006
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Rep. Hoekstra, Peter [R-MI-2]	R · MI		May 18, 2006
Rep. Kind, Ron [D-WI-3]	D · WI		May 18, 2006
Rep. Nadler, Jerrold [D-NY-8]	D · NY		May 18, 2006
Rep. Neal, Richard E. [D-MA-2]	D · MA		May 18, 2006
Rep. Oberstar, James L. [D-MN-8]	D · MN		May 18, 2006
Rep. Pickering, Charles W. "Chip" [R-MS-3]	R · MS		May 18, 2006
Rep. Ramstad, Jim [R-MN-3]	R · MN		May 18, 2006
Rep. Rothman, Steven R. [D-NJ-9]	D · NJ		May 18, 2006
Rep. Sherwood, Don [R-PA-10]	R · PA		May 18, 2006
Rep. Smith, Christopher H. [R-NJ-4]	R · NJ		May 18, 2006
Rep. Strickland, Ted [D-OH-6]	D · OH		May 18, 2006
Rep. Taylor, Gene [D-MS-4]	D · MS		May 18, 2006
Rep. Walsh, James T. [R-NY-25]	R · NY		May 18, 2006
Rep. Woolsey, Lynn C. [D-CA-6]	D · CA		May 18, 2006
Rep. Cardin, Benjamin L. [D-MD-3]	D · MD		May 22, 2006
Rep. Coble, Howard [R-NC-6]	R · NC		May 22, 2006
Rep. Cuellar, Henry [D-TX-28]	D · TX		May 22, 2006
Rep. Delahunt, William D. [D-MA-10]	D · MA		May 22, 2006
Rep. Ehlers, Vernon J. [R-MI-3]	R · MI		May 22, 2006
Rep. Emerson, Jo Ann [R-MO-8]	R · MO		May 22, 2006
Rep. Ferguson, Mike [R-NJ-7]	R · NJ		May 22, 2006
Rep. Fossella, Vito [R-NY-13]	R · NY		May 22, 2006
Rep. Franks, Trent [R-AZ-2]	R · AZ		May 22, 2006
Rep. Gerlach, Jim [R-PA-6]	R · PA		May 22, 2006
Rep. Gonzalez, Charles A. [D-TX-20]	D · TX		May 22, 2006
Rep. Israel, Steve [D-NY-2]	D · NY		May 22, 2006
Rep. Johnson, Timothy V. [R-IL-15]	R · IL		May 22, 2006
Rep. King, Peter T. [R-NY-3]	R · NY		May 22, 2006
Rep. LaHood, Ray [R-IL-18]	R · IL		May 22, 2006
Rep. Langevin, James R. [D-RI-2]	D · RI		May 22, 2006
Rep. Lewis, John [D-GA-5]	D · GA		May 22, 2006
Rep. Lewis, Ron [R-KY-2]	R · KY		May 22, 2006

Cosponsor	Party / State	Role	Date Joined
Rep. Lucas, Frank D. [R-OK-3]	R · OK		May 22, 2006
Rep. Matsui, Doris O. [D-CA-5]	D · CA		May 22, 2006
Rep. McIntyre, Mike [D-NC-7]	D · NC		May 22, 2006
Rep. Miller, George [D-CA-7]	D · CA		May 22, 2006
Rep. Platts, Todd Russell [R-PA-19]	R · PA		May 22, 2006
Rep. Schakowsky, Janice D. [D-IL-9]	D · IL		May 22, 2006
Rep. Souder, Mark E. [R-IN-3]	R · IN		May 22, 2006
Rep. Sullivan, John [R-OK-1]	R · OK		May 22, 2006
Rep. Ackerman, Gary L. [D-NY-5]	D · NY		May 23, 2006
Rep. Holden, Tim [D-PA-17]	D · PA		May 23, 2006
Rep. Kennedy, Mark R. [R-MN-6]	R · MN		May 23, 2006
Rep. Larsen, Rick [D-WA-2]	D · WA		May 23, 2006
Rep. Meehan, Martin T. [D-MA-5]	D · MA		May 23, 2006
Rep. Olver, John W. [D-MA-1]	D · MA		May 23, 2006
Rep. Rahall, Nick J., II [D-WV-3]	D · WV		May 23, 2006
Rep. Weldon, Curt [R-PA-7]	R · PA		May 23, 2006
Rep. Wynn, Albert Russell [D-MD-4]	D · MD		May 23, 2006
Rep. Andrews, Robert E. [D-NJ-1]	D · NJ		May 25, 2006
Rep. Cooper, Jim [D-TN-5]	D · TN		May 25, 2006
Rep. Costa, Jim [D-CA-20]	D · CA		May 25, 2006
Rep. Dent, Charles W. [R-PA-15]	R · PA		May 25, 2006
Rep. Doyle, Michael F. [D-PA-14]	D · PA		May 25, 2006
Rep. Etheridge, Bob [D-NC-2]	D · NC		May 25, 2006
Rep. Graves, Sam [R-MO-6]	R · MO		May 25, 2006
Rep. Meeks, Gregory W. [D-NY-6]	D · NY		May 25, 2006
Rep. Murphy, Tim [R-PA-18]	R · PA		May 25, 2006
Rep. Sessions, Pete [R-TX-32]	R · TX		May 25, 2006
Rep. Simmons, Rob [R-CT-2]	R · CT		May 25, 2006
Rep. Stark, Fortney Pete [D-CA-13]	D · CA		May 25, 2006
Rep. Tierney, John F. [D-MA-6]	D · MA		May 25, 2006
Rep. Berman, Howard L. [D-CA-28]	D · CA		Jun 6, 2006
Rep. Burton, Dan [R-IN-5]	R · IN		Jun 6, 2006
Rep. Capito, Shelley Moore [R-WV-2]	R · WV		Jun 6, 2006
Rep. DeFazio, Peter A. [D-OR-4]	D · OR		Jun 6, 2006
Rep. Drake, Thelma D. [R-VA-2]	R · VA		Jun 6, 2006
Rep. Duncan, John J., Jr. [R-TN-2]	R · TN		Jun 6, 2006
Rep. Garrett, Scott [R-NJ-5]	R · NJ		Jun 6, 2006
Rep. Kanjorski, Paul E. [D-PA-11]	D · PA		Jun 6, 2006
Rep. Kennedy, Patrick J. [D-RI-1]	D · RI		Jun 6, 2006
Rep. Moran, Jerry [R-KS-1]	R · KS		Jun 6, 2006
Rep. Ney, Robert W. [R-OH-18]	R · OH		Jun 6, 2006
Rep. Price, David E. [D-NC-4]	D · NC		Jun 6, 2006

Cosponsor	Party / State	Role	Date Joined
Rep. Pryce, Deborah [R-OH-15]	R · OH		Jun 6, 2006
Rep. Sabo, Martin Olav [D-MN-5]	D · MN		Jun 6, 2006
Rep. Serrano, Jose E. [D-NY-16]	D · NY		Jun 6, 2006
Rep. Emanuel, Rahm [D-IL-5]	D · IL		Jun 7, 2006
Rep. Inslee, Jay [D-WA-1]	D · WA		Jun 8, 2006
Rep. Latham, Tom [R-IA-4]	R · IA		Jun 8, 2006
Rep. McKeon, Howard P. "Buck" [R-CA-25]	R · CA		Jun 8, 2006
Rep. Miller, Brad [D-NC-13]	D · NC		Jun 8, 2006
Rep. LaTourette, Steven C. [R-OH-14]	R · OH		Jun 13, 2006
Rep. Ryan, Tim [D-OH-17]	D · OH		Jun 13, 2006
Rep. Slaughter, Louise McIntosh [D-NY-28]	D · NY		Jun 13, 2006
Rep. Clyburn, James E. [D-SC-6]	D · SC		Jun 22, 2006
Rep. Matheson, Jim [D-UT-2]	D · UT		Jun 22, 2006
Rep. Peterson, Collin C. [D-MN-7]	D · MN		Jun 22, 2006
Rep. Walden, Greg [R-OR-2]	R · OR		Jun 22, 2006
Rep. Lowey, Nita M. [D-NY-18]	D · NY		Jun 29, 2006
Rep. Ross, Mike [D-AR-4]	D · AR		Jun 29, 2006
Rep. Young, C. W. Bill [R-FL-10]	R · FL		Jun 29, 2006
Rep. Aderholt, Robert B. [R-AL-4]	R · AL		Jul 12, 2006
Rep. Berry, Marion [D-AR-1]	D · AR		Jul 12, 2006
Rep. Doolittle, John T. [R-CA-4]	R · CA		Jul 12, 2006
Rep. Jackson, Jesse L., Jr. [D-IL-2]	D · IL		Jul 12, 2006
Rep. Schwartz, Allyson Y. [D-PA-13]	D · PA		Jul 17, 2006
Rep. Gutknecht, Gil [R-MN-1]	R · MN		Jul 26, 2006
Rep. Payne, Donald M. [D-NJ-10]	D · NJ		Jul 28, 2006
Rep. Brown, Henry E., Jr. [R-SC-1]	R · SC		Sep 6, 2006
Rep. Butterfield, G. K. [D-NC-1]	D · NC		Sep 6, 2006
Rep. McCollum, Betty [D-MN-4]	D · MN		Sep 6, 2006
Rep. Smith, Adam [D-WA-9]	D · WA		Sep 6, 2006
Rep. Pitts, Joseph R. [R-PA-16]	R · PA		Sep 13, 2006
Rep. Pomeroy, Earl [D-ND-At Large]	D · ND		Sep 13, 2006
Rep. Spratt, John M., Jr. [D-SC-5]	D · SC		Sep 13, 2006
Rep. Green, Gene [D-TX-29]	D · TX		Sep 14, 2006
Rep. Reichert, David G. [R-WA-8]	R · WA		Sep 19, 2006
Rep. Bradley, Jeb [R-NH-1]	R · NH		Sep 21, 2006
Rep. Holt, Rush [D-NJ-12]	D · NJ		Sep 26, 2006
Rep. Murtha, John P. [D-PA-12]	D · PA		Sep 26, 2006
Rep. Bean, Melissa L. [D-IL-8]	D · IL		Sep 29, 2006
Rep. Hooley, Darlene [D-OR-5]	D · OR		Sep 29, 2006
Rep. Porter, Jon C. [R-NV-3]	R · NV		Sep 29, 2006
Rep. Watt, Melvin L. [D-NC-12]	D · NC		Sep 29, 2006
Rep. Bono, Mary [R-CA-45]	R · CA		Nov 13, 2006

Cosponsor	Party / State	Role	Date Joined
Rep. Hunter, Duncan [R-CA-52]	R · CA		Nov 13, 2006
Rep. Kaptur, Marcy [D-OH-9]	D · OH		Nov 13, 2006
Rep. Myrick, Sue Wilkins [R-NC-9]	R · NC		Nov 13, 2006
Rep. Wolf, Frank R. [R-VA-10]	R · VA		Nov 13, 2006
Rep. Fattah, Chaka [D-PA-2]	D · PA		Dec 8, 2006
Rep. Sherman, Brad [D-CA-27]	D · CA		Dec 8, 2006

## Committee Activity

Committee	Chamber	Activity	Date
Energy and Commerce Committee	House	Referred to	Oct 17, 2005

## Subjects & Policy Tags

### Policy Area:

Health

## Related Bills

Bill	Relationship	Last Action
109 S 1353	Identical bill	<b>Jun 30, 2005:</b> Read twice and referred to the Committee on Health, Education, Labor, and Pensions. (text of measure as introduced: CR 7/1/2005 S7836-7837)

## Summary (as of Oct 7, 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**

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- **Oct 17, 2005:** Referred to the Subcommittee on Health.
- **Oct 7, 2005:** Introduced in House
- **Oct 7, 2005:** Sponsor introductory remarks on measure. (CR E2078)
- **Oct 7, 2005:** Referred to the House Committee on Energy and Commerce.

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