

## 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)

| Cosponsor                                   | Party / State | Role | Date Joined |
|---|---------------|------|-------------|
| Del. Bordallo, Madeleine Z. [D-GU-At Large] | D · GU        |      | Oct 7, 2005 |
| Rep. Abercrombie, Neil [D-HI-1]             | D · HI        |      | Oct 7, 2005 |
| Rep. Allen, Thomas H. [D-ME-1]              | D · ME        |      | Oct 7, 2005 |
| Rep. Berkley, Shelley [D-NV-1]              | D · NV        |      | Oct 7, 2005 |
| Rep. Brady, Robert A. [D-PA-1]              | D · PA        |      | Oct 7, 2005 |
| Rep. Brown, Sherrod [D-OH-13]               | D · OH        |      | Oct 7, 2005 |
| Rep. Calvert, Ken [R-CA-44]                 | R · CA        |      | Oct 7, 2005 |
| Rep. Capps, Lois [D-CA-23]                  | D · CA        |      | Oct 7, 2005 |
| Rep. Capuano, Michael E. [D-MA-8]           | D · MA        |      | Oct 7, 2005 |
| Rep. Carson, Julia [D-IN-7]                 | D · IN        |      | Oct 7, 2005 |
| Rep. Crowley, Joseph [D-NY-7]               | D · NY        |      | Oct 7, 2005 |
| Rep. DeLauro, Rosa L. [D-CT-3]              | D · CT        |      | Oct 7, 2005 |
| Rep. Eshoo, Anna G. [D-CA-14]               | D · CA        |      | Oct 7, 2005 |
| Rep. Filner, Bob [D-CA-51]                  | D · CA        |      | Oct 7, 2005 |
| Rep. Foley, Mark [R-FL-16]                  | R · FL        |      | Oct 7, 2005 |
| 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 |
| Rep. Jackson-Lee, Sheila [D-TX-18]          | D · TX        |      | Oct 7, 2005 |
| Rep. Jefferson, William J. [D-LA-2]         | D · LA        |      | Oct 7, 2005 |
| Rep. Kucinich, Dennis J. [D-OH-10]          | D · OH        |      | Oct 7, 2005 |
| Rep. Lantos, Tom [D-CA-12]                  | D · CA        |      | Oct 7, 2005 |
| Rep. Lynch, Stephen F. [D-MA-9]             | D · MA        |      | Oct 7, 2005 |
| Rep. McDermott, Jim [D-WA-7]                | D · WA        |      | Oct 7, 2005 |
| Rep. McHugh, John M. [R-NY-23]              | R · NY        |      | Oct 7, 2005 |
| Rep. McNulty, Michael R. [D-NY-21]          | D · NY        |      | Oct 7, 2005 |
| Rep. Moore, Dennis [D-KS-3]                 | D · KS        |      | Oct 7, 2005 |
| Rep. Owens, Major R. [D-NY-11]              | D · NY        |      | Oct 7, 2005 |
| Rep. Rangel, Charles B. [D-NY-15]           | D · NY        |      | Oct 7, 2005 |
| Rep. Ros-Lehtinen, Ileana [R-FL-18]         | R · FL        |      | Oct 7, 2005 |
| Rep. Ruppersberger, C. A. Dutch [D-MD-2]    | D · MD        |      | Oct 7, 2005 |
| Rep. Rush, Bobby L. [D-IL-1]                | D · IL        |      | Oct 7, 2005 |
| Rep. Sanders, Bernard [I-VT-At Large]       | I · VT        |      | Oct 7, 2005 |
| Rep. Schiff, Adam B. [D-CA-29]              | D · CA        |      | Oct 7, 2005 |
| Rep. Scott, David [D-GA-13]                 | D · GA        |      | Oct 7, 2005 |
| Rep. Shays, Christopher [R-CT-4]            | R · CT        |      | Oct 7, 2005 |
| Rep. Shimkus, John [R-IL-19]                | R · IL        |      | Oct 7, 2005 |
| 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 |

| Cosponsor                                  | Party / State | Role | Date Joined  |
|--|---------------|------|--------------|
| Rep. Wasserman Schultz, Debbie [D-FL-20]   | D · FL        |      | Oct 7, 2005  |
| Rep. Waxman, Henry A. [D-CA-30]            | D · CA        |      | Oct 7, 2005  |
| Rep. Weiner, Anthony D. [D-NY-9]           | D · NY        |      | Oct 7, 2005  |
| Rep. Wexler, Robert [D-FL-19]              | D · FL        |      | Oct 7, 2005  |
| Rep. Whitfield, Ed [R-KY-1]                | R · KY        |      | Oct 7, 2005  |
| Rep. McCarthy, Carolyn [D-NY-4]            | D · NY        |      | Oct 17, 2005 |
| 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 |
| Rep. Solis, Hilda L. [D-CA-32]             | D · CA        |      | Nov 17, 2005 |
| Rep. Shaw, E. Clay, Jr. [R-FL-22]          | R · FL        |      | Nov 18, 2005 |
| Rep. Mollohan, Alan B. [D-WV-1]            | D · WV        |      | Dec 6, 2005  |
| Rep. Maloney, Carolyn B. [D-NY-14]         | D · NY        |      | Dec 8, 2005  |
| 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 |

| Cosponsor                                  | Party / State | Role | Date Joined  |
|--|---------------|------|--------------|
| Rep. Chandler, Ben [D-KY-6]                | D · KY        |      | May 18, 2006 |
| Rep. Clay, Wm. Lacy [D-MO-1]               | D · MO        |      | May 18, 2006 |
| Rep. Costello, Jerry F. [D-IL-12]          | D · IL        |      | May 18, 2006 |
| 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 |
| Rep. Hinojosa, Ruben [D-TX-15]             | D · TX        |      | May 18, 2006 |
| 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:** 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.