



**The ALS Association**  
*National Office*

## Media Release

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### **Congress Votes to Create National Registry for Lou Gehrig's Disease; President Expected to Sign ALS Association Priority Into Law**

**CALABASAS HILLS, Calif. (September 26, 2008)** – Congress took a major step in the fight against Lou Gehrig's Disease today when the House of Representatives passed the ALS Registry Act (S. 1382). The legislation, which passed the U.S. Senate on September 23, now heads to President Bush, who is expected to sign the bill into law.

The ALS Registry Act would establish the first ever national patient registry of people with Lou Gehrig's Disease, or amyotrophic lateral sclerosis, to be administered by the Centers for Disease Control and Prevention. The registry would collect information leading to the cause, treatment and cure of the deadly neurological disease that took the life of baseball legend Lou Gehrig in 1941.

“The ALS Association and people with ALS across the country have been working with Congress for nearly four years to pass this critical legislation,” said Gary Leo, president and CEO of The ALS Association. “It's long overdue. Today, the U.S. Congress has made it clear that our nation is committed to finding a treatment and cure for this horrific disease.”

It has been nearly six decades since Lou Gehrig lost his life to ALS. Although more is known about the disease today, there is no known cause or means of prevention, nor is there an effective treatment or a cure. In fact, the prognosis for a person living with ALS today is nearly the same as it was for Gehrig: death in an average of two to five years.

The ALS Registry Act enjoyed broad bipartisan support thanks to the grassroots efforts of thousands of people with ALS and their families who reached out to Congress as well as the efforts of Congressional leaders to shepherd the bill through the legislative process.

“Today's victory could not have been accomplished without the active involvement of people with ALS and their families,” said Steve Gibson, The Association's vice president of Government Relations and Public Affairs. “And it could not have passed without the bipartisan leadership from Senate Majority Leader Harry Reid (D-NV), Senator John Warner (R-VA), Senator Lisa Murkowski (R-AK), Representative Eliot Engel (D-NY), and Representative Lee Terry (R-NE). The ALS community

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deeply appreciates their commitment to our cause and their tireless efforts which have directly led to today's victory. ”

Gibson also noted that the bill will benefit our nation's military veterans. “Although ALS can strike anyone, regardless of their age, gender, race or nationality, recent studies have shown that the disease strikes military veterans at approximately double the rate as the general population. A national registry will enable us to learn why our veterans are at greater risk of ALS so that we can take action to help them and to protect the lives of our heroes serving in the military today. We urge President Bush to sign this critical legislation into law.”

The ALS Registry Act was introduced in the Senate by Reid and Warner and in the House of Representatives by Engel and Terry. As Congress sent the legislation to President Bush, members of Congress from both sides of the aisle acknowledged the more than three-year fight that led to today's action and noted the important role a national ALS registry will play in the continuing fight for a treatment and cure.

“After years of obstruction, both chambers of Congress approved our legislation that will give hope to those affected by ALS,” Reid said. “This bill will arm scientists with the tools they need to make progress in the search for a cure for ALS, or possibly a way to prevent this devastating disease in the first place. I am so pleased that we were finally able to pass this legislation on behalf of all of the individuals and families who have shown exceptional courage and grace in the face of this difficult illness.”

“The great Lou Gehrig put a national face on ALS over 65 years ago, and my own family was devastated by the death of my grandmother, Dora Engel, who is believed to have passed away as a result of ALS in her 50s,” Engel said. “The establishment of a registry will bring new hope to thousands of patients and their families that ALS will no longer be a death sentence.”

The ALS Association is the only national not-for-profit health agency dedicated solely to the fight against ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's Disease). The ALS Association is fighting on every front – research, patient and community services, public education, and advocacy – to improve living with ALS. The mission of The Association is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

#### **Additional quotes from members of Congress:**

##### **House of Representatives**

“All diseases bring hardships on those afflicted, but ALS is particularly cruel in the quickness of the onset, the severity of the symptoms and the fatal nature of the condition.” – Rep. Lee Terry (R-NE)

##### **Senate**

“After years of hard work, I am pleased Congress has passed the ALS Registry Act. This legislation provides for the creation and maintenance of a single nationwide ALS registry. With an estimated 30,000 Americans affected by this disease at any given time and some 15 new cases of ALS diagnosed every day, this much-needed legislation will help provide hope for those affected and their families.” – Sen. John Warner (R-VA)

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“It has been nearly 70 years since Lou Gehrig’s diagnosis and almost 150 years since ALS was first detected and yet we still have no effective treatments or a cure. This is a true victory for the nearly 6,000 Americans diagnosed with ALS every year and for those we have lost to this vicious disease. While the National Institutes of Health (NIH) must continue to research ALS, in the interim, we can facilitate these efforts by providing for a national registry to help find a treatment and cure for ALS.”  
– Sen. Lisa Murkowski (R-AK)

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