



**The ALS Association**  
*National Office*

27001 Agoura Road, Suite 150  
Calabasas Hills, CA 91301-5104  
(818) 880-9007 FAX (818) 880-9006

## Media Release

**Contact:**  
**The ALS Association**  
Gary Wosk, Manager, Media Relations  
(818) 587-2241  
[gwosk@alsa-national.org](mailto:gwosk@alsa-national.org)

### **President Signs ALS Association Priority Into Law Legislation Creates Nationwide Registry for Lou Gehrig's Disease**

**CALABASAS HILLS, Calif. (October 10, 2008)** – The ALS Association and people living with Lou Gehrig's Disease across the country celebrated a tremendous victory as President Bush signed into law S. 1382, the ALS Registry Act, in the late afternoon on Wednesday, October 8.

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 community now has a new tool that will help us solve the mysteries of this disease,” said Gary A. Leo, president and CEO of The ALS Association. “A nationwide registry will help us learn what causes ALS, how it can be effectively diagnosed and treated, and ultimately how it can be cured. This is a tremendous victory.”

The ALS Association has been working with Congress for nearly four years to pass the ALS Registry Act, which was first introduced in 2005 by Senate Majority Leader Harry Reid (D-NV) and Senator John Warner (R-VA) and U.S. Representatives Eliot Engel (D-NY) and Lee Terry (R-NE). Thanks to their leadership, the bill passed the U.S. Senate and the House of Representatives with near unanimous support in late September.

“After years of obstruction, both chambers of Congress approved our legislation that will give hope to those affected by ALS,” Majority Leader 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.”

MORE...

The ALS Registry Act enjoyed broad bipartisan support in Congress as a result of the grassroots efforts of thousands of people with ALS and their families who reached out to Congress. Individuals like Kate Linder, star of the daytime television program, “The Young and the Restless,” also helped raise awareness and build support for the bill among the public and lawmakers alike. “I am so proud to have been part of this effort,” said Linder whose brother in-law Scott was diagnosed with ALS in 2004. “This will truly make a difference in the lives of thousands of people with ALS and those yet to be diagnosed, including our military veterans who are at greater risk of ALS.”

Steve Gibson, vice president of government relations and public affairs for The Association echoed Linder’s comments noting 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.”

Gibson also applauded the efforts of people with ALS and their families across the country who shared their stories with elected officials, giving them a first hand account of why a national ALS registry is needed. “When you meet a person with ALS and learn there is no treatment and no cure, it makes an impact,” said Gibson. “Today, we have hope due to the leadership of people like Majority Leader Reid and Congressman Engel, who stepped up to the plate and helped to lead the fight. They are true ALS advocates.”

Congressman Eliot Engel, whose grandmother, Dora Engel, is believed to have passed away as a result of ALS in her 50s, expressed the views of so many in the ALS community, saying “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.

###