

# ALS Advocacy Delivers!

Thanks to the efforts of advocates across the country who reached out to their Members of Congress to tell the ALS story, we have:

- *Enacted the ALS Registry Act and secured over \$20 million in continued funding;*
- *Advocated for historic regulations at the Department of Veterans Affairs that make ALS a service connected disease, providing **military veterans and their survivors access to the highest level of health and disability benefits;***
- *Continued funding for the ALS Research Program at the Department of Defense through an \$8 million appropriation in FY2011. A total of **over \$25 million has now been provided to the ALSRP, which is specifically designed to identify new treatments for ALS;** and*
- *Eliminated the 24-month waiting period that people disabled with ALS had to endure before they could start receiving Medicare benefits. ALS is now one of only two diseases for which the waiting period does not apply, and the waiver for ALS is the only change Congress has made to the waiting period since it was first established.*

Taken together, our advocacy efforts are advancing ALS research, improving patient care, and creating the roadmap that will lead us to a treatment and cure for this disease! Thank you to everyone in the ALS community whose persistence and year-round efforts made these victories possible!

## **Stay Involved!**

Despite these victories, we face many challenges as we work to continue this success and accomplish our Public Policy Priorities. That's why it's absolutely critical that you stay involved in our efforts. As ALSA Advocates, you are making a difference, so please keep an eye out for our action alerts throughout the year and urge others to join our cause by becoming ALSA Advocates too! We must continue these and other vital programs!

## **National ALS Registry**

As of October 2010, every living person with ALS in United States can self-enroll in the National ALS Registry. This Registry may be the single largest ALS research project ever created and is designed to identify ALS cases from throughout the entire United States. Most important, **the Registry is collecting critical information about the disease that will improve care for people with ALS and help us learn what causes the disease, how it can be treated and even prevented.**

The ALS Association led the fight to establish the National ALS Registry, working with Congress to enact the ALS Registry Act and secure over \$20 million in federal funding to design, build and implement the National ALS Registry at the Centers for Disease Control and Prevention/Agency for Toxic Substances and Disease Registry (CDC/ATSDR).

### **ALS Research**

The ALS Association is a champion for additional funding for ALS research. **Our efforts have generated more than \$600 million in government funding for ALS research**, increasing from \$15 million in 1998 to nearly \$80 million in 2010. We have partnered with Congress to appropriate nearly \$25 million for the ALS Research Program at the Department of Defense. The ALSRP is the only ALS specific program at DOD and is focused on translational research, leading to new treatments for the disease. We also advocated for increased funding for the National Institutes of Health as part of the 2009 Economic Stimulus Package, leading to nearly \$25 million in grants awarded for ALS research over two years.

### **National ALS Advocacy Day**

**Join us in Washington, DC in May for the National ALS Advocacy Day and Public Policy Conference.** This empowering event has directly led to our successes, including the ALS registry and respite care. In addition to helping to secure funding and support for ALS research and patient services, attendees at the 2012 conference also will learn the latest updates on programs made possible through our advocacy, like the national ALS registry, DOD research and stem cell research.