The Roadmap to a Cure
2010 National ALS Advocacy Day and Public Policy Conference

In May, hundreds of advocates from across the country joined together in Washington, DC for The ALS Association’s 2010 National ALS Advocacy Day and Public Policy Conference. The conference is part of a year-round strategic effort by The ALS Association to improve patient care, advance research and empower people with ALS. By leveraging the resources of the federal government, which is the single largest source of ALS research funding and patient services in the world, the Advocacy Conference is creating the Roadmap that will lead to a cure.

And whether you were a first time attendee or a conference veteran, everyone who attended quickly realized that:

*The power of the conference is found in the people attending and the knowledge that families impacted by ALS are not alone in the fight – that together they can make a difference.*

And make a difference is just what advocates did as they flooded the Hall of Congress to tell the ALS story and continue the roadmap to a cure. This year’s goals:

- To increase funding for the national ALS Registry, which may become the single largest ALS research project ever created, with the potential to not only find the causes of the disease, but how it can be treated and even prevented; and
- Double funding for the ALS Research Program (ALSRP) at the Department of Defense (DOD), a program whose sole mission is to develop a treatment for ALS.

Judging by the feedback received from meetings with nearly 400 Members of Congress, it is clear that advocates made an impact as Members of Congress, both Democrats and Republicans, signaled strong support for both of our priority issues.

However, the success of the conference is not only found in the results that are produced on Capitol Hill, but also in the ability of the conference to empower people with ALS: to give them the opportunity to play an active role in the fight against the disease - to fight back against ALS.
And by all accounts, the conference succeeded. The sense of empowerment was not only felt walking the Halls of Congress. It was present on each day of the conference – whether during the conference’s opening session where advocates from across the country shared their local success on the as they boarded the bus that would take them on the road to a cure, the “Prep for the Hill” session or even the Mother’s Day BBQ where attendees had the opportunity to meet hundreds of others who share the same experiences and the same hopes in the journey toward a treatment.

**Research and Policy Breakout Sessions**

Prior to the Hill visits advocates heard about the progress towards a treatment that have been made possible by advocacy, including:

- The Centers for Disease Control and Prevention announced that people with ALS will be able to self enroll in the National ALS Registry beginning in the fall of 2010 (see [http://www.alsa.org/files/pdf/Registry_0610.pdf](http://www.alsa.org/files/pdf/Registry_0610.pdf)). At the request of the Agency, during the Advocacy Conference, several PALS also tested the online website that will be used by people with ALS to enroll in the registry.
- Researchers funded by the ALSRP at the Department of Defense shared the latest progress as this critical program fills a gap in the drug development pipeline, speeding the search for a treatment.
- Dr. Story Landis, Director of the National Institutes of Neurological Disorders and Stroke, the single largest source of ALS research funding, and several other leaders from the National Institutes of Health (NIH) shared exciting developments at the Agency, including the TRND (Therapeutics for Rare and Neglected Diseases) program and the Cures Acceleration Network, both of which are designed to increase and accelerate the search for a treatment for ALS and other diseases for which effective treatments do not exist.

Breakout sessions also delivered more information to attendees about veterans benefits The Association helped secure in 2008 for military veterans with ALS; Congressional funding for respite care; and the promising therapies in clinical trials. Sessions focused on clinical care included the latest advances in respiratory care and brain computer interface technologies. And for the fourth consecutive year, The Association held a breakout session designed to help children and families become involved in advocacy efforts.

**Congressional Leaders, Advocates Honored in the Fight Against ALS**

At the Celebration of Excellence Breakfast, advocates were joined by two United States Senators who have helped lead the fight against ALS on Capitol Hill. Senator Bob Casey (D-PA) was awarded the Henry A. Wallace Award for championing funding for the ALS Research Program at the Department of Defense. And Senator Lisa Murkowski (R-AK) was on hand to honor her cousin Jenny Dwyer from Washington State who received the Advocate of the
Year Award for her efforts to help pass the ALS Registry Act and support her husband Pat who is living with ALS.

**ALS Association Pays Tribute to Those Lost to ALS**

While the focus of the conference was to advance ALS public policy and empower the ALS community, the annual **Candlelight Vigil** reminded attendees why we come together in Washington each year.

Held at Freedom Plaza, located on Pennsylvania Avenue just blocks from the White House and with the U.S. Capitol Building in the background, the vigil was hosted by actress **Kate Linder, star of the top daytime television drama, The Young and the Restless**. With wonderful musical interludes delivered by Washington, DC’s Duke Ellington School for the Arts Choir, several advocates shared memories of their loved ones who have been lost to the disease and paid tribute to all of those still fighting. Speakers included: **Ken McGunagle from Rhode Island** who lost his father to ALS; **Kathy Holt from Washington State** whose best friend Mark Reiman sang the National Anthem at every Major League Baseball park before succumbing to the disease; and **13 year old Andy Snyder** of West Virginia whose memories of his grandmother Lynne brought tears and smiles to the faces of all in attendance. Indeed, the vigil provided attendees with renewed purpose and once again signaled that The ALS Association is lighting the way for a treatment and cure.

For the hundreds of advocates who joined together in Washington, the 2010 Advocacy Conference was an event to remember. And it was an event that made a difference in creating the roadmap that will lead to a treatment and cure for ALS.

**Join Us in 2011!**

The ALS Association encourages the entire ALS community to join us for next year’s conference, which takes place **May 8-10, 2011**. And please participate in The Association’s year-round advocacy efforts by signing-up to become an ALS Advocate TODAY at [www.alsa.org/policy/involved.cfm](http://www.alsa.org/policy/involved.cfm).

In the meantime, we invite you to share memories and view photos taken during the conference, which are available at [www.alsa.org/policy/alsday.cfm](http://www.alsa.org/policy/alsday.cfm).