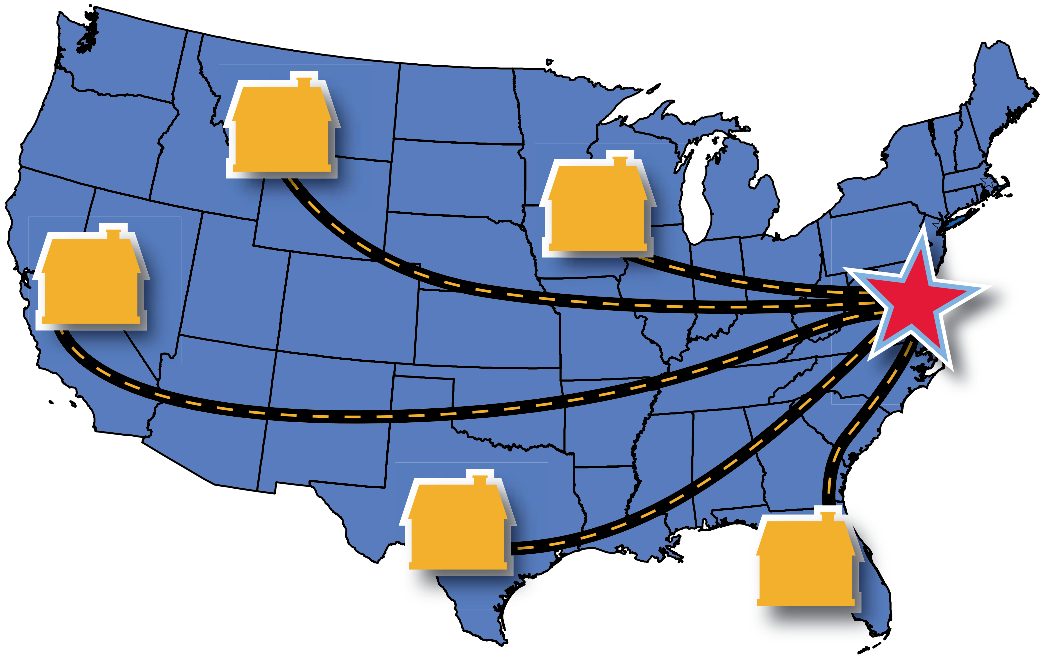
The ALS Association's
National ALS Advocacy Day and
Public Policy Conference



From
YOUR House...

roadmap to a cure

WASHINGTON, DC • MAY 9-11, 2010

...to the
PEOPLE'S HOUSE

ALS Association
Fighting Lou Gehrig's Disease

The ALS Association's Advocacy Delivers!

Dear Advocate:

The ALS Association invites you to join us as we host the 2010 National ALS Advocacy Day and Public Policy Conference in Washington, DC, May 9-11, 2010.

This powerful event has helped us to realize significant victories for people with ALS, from eliminating the 24-month Medicare waiting period to more than tripling funding for ALS research. But more must be done! So follow the signs below and help us continue to create the roadmap that will lead to a treatment and cure for ALS.

~The ALS Association

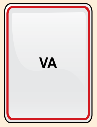
Our Advocacy Accomplishments Include:

24-Month Medicare Waiver

Enacted historic legislation to eliminate the 24-month Medicare waiting period for people with ALS, the only time Congress has amended this law.

Government Funding for ALS Research

Generated more than $425 million for ALS research over the past 10 years and increased annual government funding from just $15.1 million in 1998 to more than $60 million in 2009 alone.

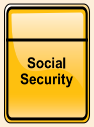


Veterans Benefits

Advanced regulations that establish ALS as a service connected disease. Veterans with ALS and their survivors now have access to more than $500 million in benefits, including monthly disability compensation and full health care.

National ALS Registry

Enacted the ALS Registry Act to create the first nationwide ALS patient registry, which may become the single largest ALS research project ever. Over $15 million appropriated to date.



Presumptive Disability Ruling

Established a presumptive disability ruling for ALS at the Social Security Administration, helping to ensure timely access to disability benefits for people with ALS.

DOD Translational Research

Partnered with Congress and the Department of Defense to create the ALS Research Program, which is the only ALS specific program at DOD and is focused on translational research seeking to find new treatments for the disease. More than $17 million appropriated in just three years.

The 2010 conference features an expanded agenda which includes exciting new sessions that deliver the latest information on ALS research and clinical care. Most important, the conference will empower you with the ability to play an active role in the advocacy efforts that can and do make a difference. Please join us in Washington, DC this May and together we can create a world without ALS.

Sunday, May 9

9:00 am-6:00 pm	Registration Desk Open at the JW Marriott Hotel
3:30 pm-4:30 pm	**Roll Call of Chapters - Opening Session** Help kick off the 2010 conference as advocates from across the country join together for this opening session and share their accomplishments and grassroots activities that continue to pave the way towards a treatment and cure for ALS.
4:30 pm-4:45 pm	Refreshment Break
4:45 pm-5:30 pm	**Preparation for the Hill** - Advocacy Department staff will provide attendees with the tips and tools they need to make a difference on Capitol Hill, including information about The ALS Association's 2010 Public Policy Priorities and how you can make the most of your meetings with Members of Congress.
6:30 pm-8:15 pm	**Mother's Day Family BBQ** - The ALS Association honors Mothers who play such a crucial role in every family that has been touched by ALS.
8:15 pm	Depart for Candlelight Vigil at Freedom Plaza
8:30 pm-9:00 pm	**Candlelight Vigil at Freedom Plaza** (across the street from the JW Marriott hotel)
9:30 pm-11:00 pm	Ice Cream Social at the JW Marriott Hotel

Monday, May 10

7:00 am-8:00 am	Continental Breakfast
7:30 am-3:00 pm	Registration Desk Open at the JW Marriott Hotel
8:15 am-11:00 am	**Plenary Session - ALS Research Update** The ALS Association has assembled a panel of world renowned experts from the ALS research and clinical communities who will discuss the advances in ALS research and clinical care made possible

by your advocacy. Topics include the National ALS Registry, exciting translational research underway at the Department of Defense and the latest developments in ALS research at the National Institutes of Health, the single largest source of ALS research funding in the world.

11:00 am-11:15 am Refreshment Break

11:15 am-12:45 pm **Breakout Session I** (select one)
Attendees will have the option of participating in one of three educational workshops.

A. ***Congressional Meetings 101 (First Timers)*** - If this is your first Advocacy Conference, this is one session you do not want to miss! ALS Association staff will walk you through everything you need to know about your day on Capitol Hill, from the location of handicap entrances at the Congressional Office Buildings to how you can most effectively share your story in your meetings with Members of Congress.

B. ***Advocacy for Children and Families*** - With speakers that include younger advocates, this interactive session empowers children and their families and provides tips and tools on how they can navigate the issues that are unique to children and participate together in the advocacy activities that can make a difference.

C. ***Caring for our Caregivers: Advances in Respite Care*** - Learn the latest developments in the effort to expand the availability of respite care for family caregivers, including the Lifespan Respite Care Act and other public and private programs.

12:45 pm-2:15 pm Strategy Lunch for Chapter/State Delegations

2:30 pm-3:45 pm **Breakout Session II** (select one)

D. ***Advocacy Tools for Chapters (Invite Only)*** - Designed for ALS Association Chapter Executive Directors and Public Policy Chairs, this session will educate Chapters not only about State based advocacy initiatives, but also the unique role advocacy can play in advancing the Chapters' mission.

E. ***ALS Clinical Trials*** - Leading ALS researchers and clinicians will deliver updates on the most promising therapies and the role people with ALS can play in improving clinical trials.

F. ***Brain Computer Interface Technologies*** - This session will examine emerging BCI technologies and how they can help patients communicate with their families and loved ones.

G. ***Respiratory Research*** - Join us to hear the latest advances in respiratory research and care.

3:45 pm-4:00 pm Refreshment Break

4:00 pm-5:15 pm **Breakout Session III** (select one)

H. ***Veterans Benefits*** - From disability and survivors' compensation to health care, this session will provide details about the vital benefits available to veterans with ALS, their families and survivors and share best practices on how ALS Association Chapters can assist veterans in navigating the VA system.

Monday, May 10 continued

I. ***Communicating with ALS*** - What's new and what's needed are just two of the questions that will be answered in this session, which will examine the options that are available and those on the horizon to help meet the communications challenges imposed by ALS.

J. ***The Cognitive Impacts of ALS*** - ALS clinicians share the latest research that is shedding light on the cognitive impacts of ALS.

K. ***FALS*** - Join others whose share the common bond of Familial ALS and learn about the progress that continues to be realized in the field.

5:30 pm Dinner (on your own)

Tuesday, May 11

7:30 am-9:00 am **Celebration of Excellence Breakfast and Awards Presentation**
As you prepare to meet with Members of Congress, help us recognize those advocates and government leaders who have championed our cause and helped to create the *roadmap* that is leading to a treatment and cure. A full breakfast will be provided as we present The ALS Association All-Star Award, the Jacob K. Javits Public Service Award, and the Rasmussen Advocate of the Year Award. ALS Association staff also will be available to answer any last minute questions.

8:30 am-5:00 pm Transportation to Capitol Hill

9:00 am-5:00 pm **Meetings with Members of Congress**
The Roadmap to a Cure leads to Capitol Hill today as advocates from across the country tell the ALS story to Members of Congress and urge them to join us as champions in the fight against Lou Gehrig's Disease. This is your opportunity to make a difference for everyone whose life has been touched by ALS! (If you would like assistance or have questions about scheduling Congressional meetings, please contact your local ALS Association Chapter or the Advocacy Department at advocacy@alsa-national.org or toll-free at 1-877-444-ALSA.)

Lunch (on your own)
Join fellow advocates at one of the many restaurants and cafeterias located in the Congressional office buildings and on Capitol Hill. A list of dining options, including their locations, will be provided to each attendee as part of the 2010 Advocacy Conference Handbook.

3:00 pm-7:00 pm Hospitality Room Open at the JW Marriott Hotel
Drop off your Congressional meeting reports at the hospitality room at the JW Marriott Hotel and share exciting news about your Congressional meetings with fellow advocates. Refreshments will be available.

Registration

To attend the 2010 National ALS Advocacy Day and Public Policy Conference, please register online at **www.alsa.org/policy/alsday.cfm**. If you do not have internet access, you can register by calling the Advocacy Department at **1-877-444-ALSA**.

Conference registration fees are waived for people with ALS and for one caregiver traveling with them to the Conference.

For other participants, the 2010 Conference has a **$175 non-refundable** registration fee for attendees who are affiliated with The ALS Association, an ALS Association Chapter or other affiliated organization. This fee covers a small portion of conference costs, including meals, transportation and briefing materials. Registration fees for children age 3-16 are $25. The fee for non-affiliate attendees is $350.

In order to receive the reduced registration rates, please register no later than April 9, 2010. Fees for registrations submitted after April 9, are $350 for affiliates, $700 for non-affiliates, and $50 for children age 3-16.

Sunday Only Fees

A reduced registration fee of $100 is available to those attendees who only will participate in the Conference activities on Sunday, May 9. This fee helps to offset a portion of the costs associated with May 9 conference activities and covers any or all of the following activities: Mother's Day BBQ, Ice Cream Social and first day Conference sessions. There is no fee to attend the Candlelight Vigil.

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Fighting Lou Gehrig's Disease

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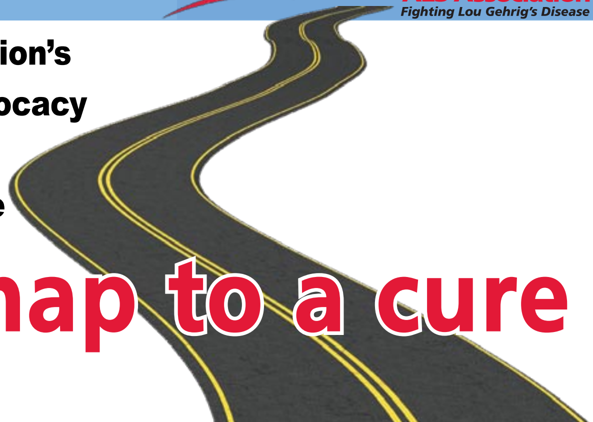

roadmap to a cure

INFORMATION

Hotel Information

Single/Double occupancy - $219.00 + tax per night

JW Marriott Hotel

(Headquarters Hotel-Registration and Sessions)
1331 Pennsylvania Ave., NW, Washington, DC 20004
800-266-9432

In order to receive the reduced conference room rate, you must reserve your room directly with the hotel by April 9, 2010.

NOTE: Reduced room rates are only available for those who already have registered to attend the conference.

Requesting an ADA Accessible Hotel Room

In order to request an ADA accessible hotel room, attendees must contact Mary Wisniewski, event planner for the conference, at **marywisniewski@comcast.net** or by phone at **202-746-0043**. Please direct additional questions about conference hotels and transportation to Mary.

If you have other questions about the conference, please contact the Advocacy Department at **advocacy@alsa-national.org** or toll-free at **1-877-444-ALSA**.