



**NATIONAL ALS ADVOCACY DAY  
AND PUBLIC POLICY CONFERENCE**

**ROADMAP TO A**



*DRIVING TO A TREATMENT*



**WASHINGTON, DC**

**MAY 13 – 15, 2012**

[www.alsa.org/advocacy](http://www.alsa.org/advocacy)

**1-877-444-ALSA**



## NATIONAL ALS ADVOCACY DAY AND PUBLIC POLICY CONFERENCE



Dear Advocate:

These are exciting times in ALS research. Scientists have made groundbreaking discoveries in the past year that have greatly increased our understanding of the disease and provided new opportunities to treat it. At the same time, several promising clinical trials are underway that could result in the first new treatments for ALS since 1995. But these breakthroughs and opportunities did not occur by chance. They occurred in part because the federal government provided the resources and the environment necessary to make advances in ALS research possible.

Indeed, thanks to advocates across the country who have told the ALS story to their elected officials, the federal government is now the single largest source of ALS research funding in the world. However, the nation's economic climate, federal budget crisis and Presidential election year politics pose significant threats to this progress.

Funding for programs throughout the federal government is being eliminated or reduced. Private funding and venture capital are increasingly scarce and the risks of pursuing ALS drug development continue to stand in the way of innovation. Despite these challenges, our advocacy with Congress provides us with the opportunity not only to continue the progress that has been made, but also to open up exciting new pathways to incentivize and accelerate the discovery of the cause, treatment and cure for ALS.

That's why The ALS Association invites you to join us in Washington, DC as the ALS community unites for the 2012 National ALS Advocacy Day and Public Policy Conference, May 13-15, 2012. Your participation is critical! Without it, the progress we have realized may not continue and the fight against ALS may fall victim to politics and budget cuts. You have made a difference through advocacy. And your help is needed now more than ever. So please join us in Washington and help us continue to create the roadmap that will lead to a treatment and cure for Lou Gehrig's Disease.



## SUNDAY, MAY 13

### PRE-CONFERENCE ACTIVITIES

**9:00 am – 8:00 pm**

**Registration Desk Open** at the JW Marriott Hotel

**10:00 am – 1:00 pm**

**Familial ALS Summit** For the first time, The ALS Association is hosting a special pre-conference session devoted to addressing the issues that are unique to families impacted by familial ALS (fALS). The inaugural fALS Summit will include presentations by noted fALS researchers as well as genetic counselors. The Summit will be an interactive session featuring discussions on the latest developments in research, such as the discovery of chromosome 9. It also will provide attendees an opportunity to meet and network with other families from across the country who share the unique bond of familial ALS.

**12:00 pm – 2:00 pm**

**ALS Association Chapter Executive Director and Public Policy Chair Roundtable** (luncheon by invitation only)

**2:00 pm – 8:00 pm**

**ALSA Marketplace Open (in the Exhibit Hall)** The ALS Association Marketplace is located in the Exhibit Hall just outside of the conference meeting rooms and is a place where attendees can learn about various products and services that are needed by people with ALS and their families and which are provided by the sponsors of the Public Policy Conference.

### CONFERENCE OPENS

**3:30 pm – 4:30 pm**

**Roll Call of Chapters-Opening Session** Advocates from every corner of the country unite for this energetic convention-style session to open the 2012 conference.

**4:30 pm – 4:45 pm**

**Refreshment Break**

**4:45 pm – 5:30 pm**

**Preparation for the Hill** You have the ability to make a difference. The Public Policy Department staff will review The ALS Association's 2012 public policy priorities and give you the tools and information you need to deliver a loud and clear message to Capitol Hill.

**6:30 pm - 8:15 pm**

**Mother's Day Family BBQ** The ALS Association pays tribute to Mothers who play such a crucial role in every family that has been touched by ALS.

**8:15 pm**

**Depart for Candlelight Tribute Rally** at Freedom Plaza

**8:30 pm – 9:00 pm**

**Candlelight Tribute Rally** 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 14

**8:00 am – 4:00 pm**

**Registration Desk Open** at the JW Marriott Hotel

**8:00 am - 9:00 am**

**Continental Breakfast**

**8:00 am – 6:00 pm**

**ALSA Marketplace Open**

**9:15 am – 10:45 am**

**Plenary Session I: Government ALS Research** People with ALS and their families have helped to generate more than \$650 million in government funding for ALS research since The ALS Association established an office in Washington, DC. In fact, today the federal government is the single largest source of ALS research funding in the world. Join us for this plenary session to learn the latest on how government programs, such as the National ALS Registry and the ALS Research Program at the Department of Defense, are advancing the search for the cause, treatment and cure for ALS.

**10:45 am – 11:00 am**

**Refreshment Break**

**11:00 am – 12:30 pm**

### BREAKOUT SESSIONS

Attendees will have the option of participating in one of four educational workshops.

**A. Congressional Meetings 101 (First Timers)** Do you have questions about meetings with your Members of Congress, what to say, where to go? Don't worry! This session will answer all of your questions. The Public Policy Department will walk you through a typical Congressional meeting and share more about what you can expect during Advocacy Day on the Hill, from the location of handicap entrances at the Congressional Office Buildings to where to have lunch on Capitol Hill.

**B. Advocacy Year-Round** Although National ALS Advocacy Day takes place on May 15, advocacy is not a one-day activity. Participate in this session to learn what you can do when you return home from Washington DC and what you can do throughout the year to continue the fight against ALS.

**C. Veterans Benefits** Thanks to the efforts of advocates nationwide, military veterans with ALS, their families and survivors are eligible to receive significant benefits from the Department of Veterans Affairs. This session will provide vital information about the benefits that are available, from health care and disability benefits to housing grants and education assistance. Participants also will learn how they can navigate the claims process to ensure they receive the benefits they need when they need them.

**D. Human Genomics 101: An Overview and its Applications for ALS Research** This session will present basic concepts of

human genetics and genomics, focusing on new discoveries and technologies that advance our understanding of the relationship between genes, environment and human health. Special attention will be given to recent findings related to ALS. If you want to gain a deeper knowledge of genomics, but have been stymied by jargon or memories of that high school biology class, take heart: this discussion cuts through the vocabulary and provides the information in an engaging and relevant way.

**12:30 pm – 1:45 pm**

**Strategy Lunch for Chapter/State Delegations**

**2:00 pm – 2:45 pm**

**Plenary Session II: Advancing the Search for a Treatment:**

**The MODDERN Cures Solution and PDUFA** Did you know that hundreds of thousands of potential treatments for ALS currently are sitting untouched on the lab shelf simply because they lack adequate patent protection? Participate in this plenary session to learn how the MODDERN Cures Solution, introduced by Congressman Leonard Lance (R-NJ), will take these ideas off the shelf and accelerate the search for a treatment for ALS. The session also will discuss the reauthorization of the Prescription Drug User Fee Act (PDUFA) and provisions specifically designed to address the needs of rare diseases.

**2:45 pm – 3:30 pm**

**Plenary Session III: The Biology of ALS and the**

**Significance of Chromosome 9** Have you ever found yourself asking ‘what does that mean’ after reading an article about the latest discovery in ALS research? You’re not alone! We’ll give you the basics in the biology of ALS and what it all means, with a particular focus on the significance of the recent discovery of chromosome 9.

**3:30 pm – 4:30 pm**

**ALSA Marketplace Open** (refreshments in Exhibit Hall)

**4:00 pm – 5:30 pm**

**Plenary Session IV: ALS Clinical Trials**

Several exciting potential treatments for ALS currently are in clinical trials throughout the world. In this session, you’ll hear the latest news about the trials from the researchers themselves during this interactive discussion featuring representatives from Biogen Idec, Cytokinetics, ISIS, and Neuralstem.

**5:45 pm – 7:15 pm**

**ALS Association Town Hall Meeting** All registered attendees are invited to join The ALS Association’s senior leadership for this Town Hall Meeting. Jay Daugherty, Chairman of The ALS Association Board of Trustees and Jane Gilbert, President & CEO, will take your questions and ideas and candidly discuss our mission and vision to create a world without ALS.

**7:15 pm**

**Dinner** (on your own)

## TUESDAY, MAY 15

**7:30 am – 9:00 am**

**Celebration of Excellence Breakfast and Awards**

**Presentation** The ALS Association will recognize advocates, Members of Congress and other government leaders who have helped to champion the fight against ALS and whose efforts are creating the roadmap that will lead to a treatment and cure. A full breakfast is served as we present The ALS Association All-Star Award, the Jacob K. Javits Public Service Award, and the Rasmussen Advocate of the Year Award. The breakfast also is an opportunity to ask any last-minute questions prior to the meetings on Capitol Hill.

**8:30 am – 5:30 pm**

**Transportation to and from Capitol Hill** (Pennsylvania Ave. exit of the hotel)

**9:00 am - 5:00 pm**

**Meetings with Members of Congress** Share the ALS story on Capitol Hill! Advocates from across the country will meet with Members of Congress to let them know why more must be done in the fight against this disease. (If you would like assistance or have questions about scheduling Congressional meetings, please contact your local ALS Association Chapter or the Public Policy Department at [advocacy@alsa-national.org](mailto:advocacy@alsa-national.org) or toll-free at 1-877-444-ALSA.)

**Lunch** (on your own)

**5:30 pm**

**Last Bus Departs Capitol Hill**

**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. Light refreshments will be available.





# ALS Association Advocacy

## MAKING A DIFFERENCE BY THE NUMBERS

Thanks to the thousands of people with ALS and their families, we are making a difference. The numbers below show the power of your advocacy...

## PARTICIPATE IN ALS RESEARCH

The ALS Association is pleased to once again offer conference attendees an opportunity to participate in an exciting research project being conducted by the National Institutes of Health (NIH). On Monday, May 14, at 8:00 am, 10:00 am and noon, people with ALS may provide blood samples and complete a questionnaire as part of the study. The purpose of the study is to learn more about the causes of the disease – not to test a potential treatment.

Researchers are particularly interested in collecting blood samples from those with familial ALS; however, researchers also will collect samples from others with the disease. These samples, which will be stored at the National Institute of Neurological Disorders and Stroke (NINDS) genetic repository, will be used to increase our understanding of ALS, and will support research conducted by scientists around the world.

If you plan to attend The ALS Association's 2012 National ALS Advocacy Day and Public Policy Conference and would like to participate in the research by giving a blood sample and meeting with scientists to complete a questionnaire, please contact the Care Services Department at [alsinfo@alsa-national.org](mailto:alsinfo@alsa-national.org) or 1-800-782-4747.



**0** Number of diseases besides ALS for which Congress has waived the 24-month Medicare waiting period. The ALS Association worked with Congress to waive the waiting period for ALS in 2001, enabling PALS to access vital Medicare benefits as soon as possible.

**31.9** Funding, in millions, in just five years that The ALS Association helped to secure for the ALS Research Program at the Department of Defense. The specific goal of the program is to find a treatment for ALS.

**130** The value, in millions, of the health and disability benefits received by veterans with ALS and their survivors in one year alone thanks to regulations that The ALS Association helped to establish at the Department of Veterans Affairs.

**500** Percentage increase in annual government funding for ALS research since 1998, the year The ALS Association established an Advocacy Department in Washington, DC.

**650** Total government funding, in millions, for ALS research over that time.

**2003** Year in which The ALS Association established a presumptive disability ruling for ALS at the Social Security Administration, helping to ensure timely access to disability benefits for people with ALS.

**2010** Year in which people with ALS began to self-enroll in the National ALS Registry, which may become the single largest ALS research program ever created.

These accomplishments could not have been achieved without the efforts of people with ALS and their families to speak out, participate in our advocacy efforts and tell the ALS story to Members of Congress.

## Registration

To attend the 2012 National ALS Advocacy Day and Public Policy Conference, please register online at [www.alsa.org/advocacy/advocacy-day](http://www.alsa.org/advocacy/advocacy-day). If you do not have internet access, you may register by calling the Public Policy 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 2012 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 to Capitol Hill and briefing materials. Registration fees for children age 3-16 are \$25. The fee for non-affiliate attendees is \$350.

**In order to receive reduced registration rates, please register no later than April 13, 2012.** Fees for registrations submitted after April 13, 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 13. This fee helps to offset a portion of the costs associated with May 13 conference activities and covers any or all of the following activities: fALS Summit, Mother's Day BBQ, Ice Cream Social and first-day conference sessions. There is no fee to attend the Candlelight Vigil, nor is there a fee for people with ALS or one caregiver traveling with them to the conference.

## Hotel Information

### **JW MARRIOTT HOTEL**

**(Headquarters Hotel-Registration and Sessions)  
1331 Pennsylvania Ave., NW  
Washington, DC 20004  
PHONE: 202-393-2000**

Single/double occupancy rate is \$233.00 + tax per night; \$263.00 + tax for triple occupancy; \$293.00 + tax for quadruple occupancy; maximum of four guests per room.

**In order to receive the reduced conference room rate, you must reserve your hotel room by April 13, 2012.**

When you register for the conference, you will be provided with a direct link to JW Marriott reservations. NOTE: Reduced room rates are only available for those who already have registered to attend the conference.

**To request an ADA accessible hotel room: In order to request an ADA accessible hotel room, you must contact Mary Wisniewski at [adaram@alsa-national.org](mailto:adaram@alsa-national.org), or by phone at 202-746-0043.** For all additional questions about hotel reservations or transportation, please contact Mary Wisniewski.

If you have additional questions about the conference, please contact the Public Policy Department at [advocacy@alsa-national.org](mailto:advocacy@alsa-national.org) or toll-free at 1-877-444-ALSA.

Activities outside of the hotel can easily be reached by using the nearest Metro station to the JW Marriott Hotel: Metro Center (Blue/Red/Yellow lines). Maps of the Metrorail system are available on-line at [www.wmata.com](http://www.wmata.com).

