



## **Schedule at a Glance**

### **2013 National ALS Advocacy Day and Public Policy Conference May 8-11, 2013**

#### **JW Marriott**

1331 Pennsylvania Avenue, NW, Washington, DC 20004

Phone: (202) 393-2000

#### **Wednesday, May 8**

7:00 am – 7:00 pm	Registration Open at the JW Marriott
1:00 pm – 3:00 pm	Chapter ED and Public Policy Chair Roundtable (Invitation only)
<i>Conference Opens</i>	
3:00 pm – 4:15 pm	Welcome Remarks/Government Research Session
4:15 pm – 4:30 pm	Refreshment Break
4:30 pm – 5:30 pm	Prep for the Hill
6:30 pm – 8:00 pm	ALSA Rally Dinner
8:00 pm – 9:00 pm	Dessert with Your Chapter/Strategy Meeting

#### **Thursday, May 9**

7:00 am - 2:00 pm	Registration Desk Open
7:00 am – 8:30 am	Continental Breakfast
8:30 am – 5:30 pm	Transportation to and from Capitol Hill
9:00 am - 5:00 pm	Meetings with Members of Congress
	Lunch (on your own)
2:00 pm – 6:00 pm	Hospitality Room Open at JW Marriott Hotel
6:00 pm – 7:00 pm	Town Hall Meeting
	Dinner on your own

**Friday, May 10**

8:00 am – 1:00 pm	Registration Open at the JW Marriott
9:00 am – 10:00 am	Continental Breakfast
9:00 am – 6:00 pm	ALSA Marketplace Open
9:30 am – 11:00 am	ALSA Research Session
11:00 am – 11:15 am	Refreshment Break
11:15 am – 12:30 pm	FDA Session
12:30 pm – 1:15 pm	ALSA Marketplace Open
1:15 pm – 2:30 pm	Lunch/Clinical Trials Session
2:45 pm – 4:30 pm	Breakout Sessions A. Human Genomics B. Veterans Benefits C. Myths and Facts about ALS D. Financial Planning
4:30 pm – 6:00 pm	Closing Reception

**Saturday, May 11: fALS Summit**

9:00 am – 9:45 am	Continental Breakfast
9:45 am – 10:00 am	Welcoming Remarks
10:00 am – 11:00 am	State of fALS Research
11:00 am – 12:00 am	Understanding fALS and Genetic Advances
12:00 pm – 1:30 pm	Networking Lunch
1:30 pm – 2:30 pm	Genetic Counseling
2:30 pm – 3:30 pm	Communicating with Children and Young Adults

# The ALS Association's 2013 Public Policy Priorities

April, 2013

- **Appropriate \$10 million to continue the National ALS Registry at the Centers for Disease Control and Prevention.**

The Administration and Congress have made the establishment of a national ALS patient registry a top priority through the enactment of the ALS Registry Act in 2008 (P.L. 110-373) and by appropriating funding to develop and implement the registry in each of the past eight years. These actions have enabled the CDC/ATSDR to launch the first ever national ALS registry. Using a variety of enrollment strategies, including online self-enrollment, the registry currently is identifying the number of cases of ALS in the U.S. and collecting data that may help us learn what causes the disease and how it can be treated, prevented and, ultimately, cured.

However, funding is necessary in FY 2014 to continue the registry, coordinate federal efforts, help people with ALS enroll in the registry and conduct outreach activities to identify ALS cases in all 50 states, including in rural and underserved areas and minority populations. Moreover, continued funding is needed to collect additional information about ALS cases, explore the possibility of adding a biorepository that collects blood and tissue samples and enable the registry to advance clinical trials to develop new treatments for the disease.

- **Appropriate \$10 million to continue the ALS Research Program (ALSRP) at the Department of Defense (DOD).**

Studies supported by the DOD, Department of Veterans Affairs, National Institutes of Health, Harvard University and the Institute of Medicine among others repeatedly have found that military veterans, regardless of branch or era of service, are approximately twice as likely to die from Lou Gehrig's Disease as those who have not served in the military.

In order to support our nation's military heroes in the fight against ALS, Congress and the DOD established the ALS Research Program (ALSRP) in FY 2007. Unlike many other research programs, which focus on basic science, the ALSRP is promoting translational research and is specifically designed to find new treatments for ALS, a disease for which an effective treatment currently does not exist. The ALSRP also is funding the best science as funding is provided on a competitive grant basis and projects are peer reviewed. While Congress has continued to appropriate funding for the ALSRP, including \$7.5 million in FY 2013, the current funding level only will be able to support three projects, yet 149 were submitted to the program last year along. As a result, under the current level more than 95% of submitted projects will not receive funding. Opportunities to discover and deliver a treatment to veterans will be lost, leaving them – and all people living with the disease – with no effective treatment option. By appropriating \$10 million for the ALSRP in FY2014, Congress can continue this vital program and take steps to ensure that our nation continues to fight for our veterans just as they fought for us.

- **Enact the MODDERN Cures Act**

Regulatory barriers and limited incentives to pursue innovation have hindered the development of new treatments and diagnostic tools for ALS and other diseases with unmet medical needs. In fact, people with ALS will die in an average of just two to five years because an effective treatment does not exist and because diagnostics and biomarkers have not been identified that can speed diagnosis, improve care and expedite the discovery of new treatments.

The MODDERN Cures Act (Modernizing our Drug and Diagnostics Evaluation and Regulatory Network) would accelerate the search for a treatment for ALS and other diseases by removing the barriers that limit medical innovation and by providing incentives to develop new treatments and diagnostic tools that can improve, prolong and, ultimately, save lives. Specifically the bill will: Encourage research on treatments, which have been set aside in the lab, but hold promise for treating diseases with unmet medical needs; remove barriers and provide incentives to develop new diagnostics; and ensure timely and appropriate reimbursement for new tests and treatments so that patients have access to the latest medical technology as soon as possible.

## **HELPFUL HINTS AND FREQUENTLY ASKED QUESTIONS**

### ➤ **Conference Hotel**

**JW Marriott** (Headquarters Hotel-Registration and Sessions)  
1331 Pennsylvania Avenue, NW  
Washington, DC 20004  
Phone: (202) 393-2000

**Other Hotels Where Advocates are Staying:** (An accessible shuttle bus will run between the JW Marriott and the other official conference hotels throughout the conference. A sign will also be displayed in the lobby of the hotels outlining the shuttle schedule.)

#### **Marriott at Metro Center**

775 12<sup>th</sup> Street, NW  
Washington, DC 20005  
Phone: 202-737-2200

#### **Homewood Suites by Hilton**

1475 Massachusetts Avenue, NW  
Washington, DC 20005  
Phone: 202-265-8000

### ➤ **Ground Transportation to the Hotel**

#### **From Ronald Reagan Washington National Airport (about 4 miles from the hotels)**

**Taxi** Depending on factors such as traffic, the number of passengers and luggage, cab fare will cost approximately \$15-20 (one-way).

**Metro** There is a Metro station just outside the Reagan National Airport terminal. Take a Blue Line train towards Largo Town Center and exit at the Metro Center station. Exit the Metro Center station using the 13TH ST NW & G ST NW exit. Go one block south on 13<sup>th</sup> Street and turn right on to Pennsylvania Avenue, NW. The hotel will be on your right. The one way Metro fare will cost between \$2.00-\$3.50 depending on what time of day you travel. Metro fare cards can be purchased at any Metro station.

**SuperShuttle** Advance reservations are encouraged, especially if wheelchair-accessible transportation is required. Roundtrip fare for two will cost approximately \$56. For reservations, visit [www.supershuttle.com](http://www.supershuttle.com) or call 800-BLUE-VAN.

#### **From Dulles International Airport (about 27 miles from the hotel)**

**Taxi** Depending on such factors as traffic and the number of passengers, cab fare will cost approximately \$60 (one-way). Washington Flyer Taxis have wheelchair-accessible vehicles that can accommodate one person in his/her wheelchair plus three additional passengers. Please call 703-572-TAXI (8294) to place a reservation.

**SuperShuttle** Advance reservations are encouraged, especially if wheelchair-accessible transportation is required. Roundtrip fare for two will cost approximately \$78. For reservations, visit [www.supershuttle.com](http://www.supershuttle.com) or call 800-BLUE-VAN.

## **From Baltimore/Washington International Airport (about 40 miles from the hotel)**

Taxi Depending on such factors as traffic, the number of passengers and luggage, cab fare will cost approximately \$90 (one-way).

SuperShuttle Advance reservations are encouraged, especially if wheelchair-accessible transportation is required. Roundtrip fare for two will cost approximately \$102. For reservations, visit [www.supershuttle.com](http://www.supershuttle.com) or call 800-BLUE-VAN.

## **From Washington's Union Station**

Two taxi companies provide handicap service to PALS in wheelchairs arriving at Union Station:

- Royal Taxi (202-398-0500)
- Yellow Taxi (202-544-1213)

While taxis can be ordered on demand for arrival within 15 to 20 minutes, we recommend that you schedule a taxi in advance.

If you experience difficulties with transportation to the conference, please contact our event planner, Mary Wisniewski, at [marywisniewski@comcast.net](mailto:marywisniewski@comcast.net) or (202) 746-0043.

### ➤ **How to Schedule an Appointment with a Member of Congress?**

Your Chapter representative is responsible for scheduling your meetings with your Members of Congress and will provide you with a final Advocacy Day schedule when you arrive in Washington. If you are not certain which Chapter represents you or have questions about your Congressional meetings, please contact the Public Policy Department using our toll-free Advocacy Day Hotline at 1-877-444-ALSA (2572). If you are not affiliated with a Chapter and have yet to contact the Public Policy Department about your meetings, please contact us immediately at 1-877-444-ALSA (2572) or contact Mark Murtagh at (202) 407-8591.

### ➤ **Preparing for Congressional Meetings**

When you arrive in Washington, you will receive an Advocacy Day Handbook that includes detailed, up-to-the-minute information to help you prepare for your meetings on Capitol Hill. It will contain information about our public policy priorities, talking points on our key issues, as well as tips and tools you can use during your Congressional meetings. We also will provide you with maps of Capitol Hill, dining options and other information to make this year's Public Policy Conference a great experience for all who attend.

During the "Prep for the Hill" session, which takes place on Wednesday, May 8 from 4:30 pm to 5:30 pm, the Public Policy Department will review our Congressional meeting strategy, including our "asks," what we will be asking Members of Congress to do for the ALS community. You will have additional time to meet with your Chapter or state delegation following the dinner on Wednesday to prepare for your meetings on Thursday.

***However, before you leave for Washington it is important that you:***

- **Think about how you will tell your personal ALS story during your meetings**  
What's your connection to the disease? How has it impacted your life, your family, etc? Share some of the many challenges of this disease. You want to humanize the disease—briefly discuss the challenges

people with ALS face in their daily life. Don't hesitate to mention the everyday things ALS patients no longer can do that the average person takes for granted, such as getting dressed, eating, bathing or even hugging a loved one. **THIS IS WHAT MEMBERS OF CONGRESS WILL REMEMBER FROM THE MEETING...**not factoids or statistics, but ***your*** personal ALS story.

- **My ALS Story:** Included in your confirmation email is a link to download a template people can use to tell their ALS story ([click here to download template](#)). Simply attach photos of loved ones who have been lost to ALS, including pictures taken before and after the onset of ALS. Also ask people with ALS who could not make the trip to Washington to add their photos and ALS story to the document. Make copies of it and bring them with you to Washington to share in your Hill meetings. Help us put a face on the disease! You can see a copy of My ALS Story on the last page of this guide.
- **Ask your friends, family and others who are not attending the Conference to sign the letter to Congress** that is included in your confirmation email or [click here to download the template letter](#). You can then deliver the letters to your Senators during your meetings on the Hill. In this way, you can help others to participate in the Conference, even if they cannot attend.
  - **Advocates:** If you bring letters with you to Washington, please be sure to provide them to your Chapter Delegation leader when you arrive at the Conference.
  - **Delegation Leaders:** The Public Policy Department requests that Chapter Delegation leaders bring signed letters to the Congressional Meeting Check-in Desk, which will be set-up next to the ALSA Marketplace at the JW Marriott Hotel. The Department will include your signed letters in the "Leave Behind" packets you will provide to Senators during your meetings. The Public Policy Department tracks the number of letters each Chapter brings with them to the Conference, but in order for your Chapter's letters to be counted, you must deliver them to the Congressional Meeting Check-in Desk!
- **Gather material from your Chapter or Support Group** to take on your visits (e.g. a brochure, a business card, a list of Board Members, a recent newsletter). Be sure to bring enough copies for each visit that you have scheduled.
- **Think about how you can assist Members of Congress and their staff.** While you will be asking Members of Congress to help people with ALS, don't forget to offer your own assistance to the office. For example, your Chapter can offer to help respond to calls and questions about ALS that the Member of Congress receives.
- **Invite Members of Congress to an upcoming Chapter event** (e.g. to kick-off your upcoming Walk, speak at your annual meeting, or visit an ALS clinic.)
- **Pack your camera**, preferably a digital, to take pictures of your meeting for your Chapter's newsletter and website.
- **Remember you are not expected to be a policy expert.** Your job is to tell your ALS story. Don't worry about the details of the issues. We will give you the key points you need to make when you arrive in Washington.

It may be convenient to bring a briefcase or tote bag to carry your items. If your Advocacy Day schedule is full of appointments, you will not have time to return to the hotel, so you will need to bring with you any

medicines or equipment that you will need. Please note, security on Capitol Hill is very tight and your belongings will be screened upon entering each Congressional office building. If you are going to the airport after your meetings, please note you must leave your luggage at the bell stand at the hotel. You cannot take your luggage with you to Capitol Hill.

### ➤ **ALS Advocacy Day App**

This year you will be able to access your Congressional meeting schedule on your iPhone, iPad, Android and Blackberry! The “Stress Free Lobby Days” app can be found in the Android Market, the Apple App Store or by going to [www.tripbuilder.com/lobbydaysapps](http://www.tripbuilder.com/lobbydaysapps) for Blackberry. **You will receive instructions on Wednesday, May 8 on how to log into your meeting schedule, but be sure to download the app prior to coming to DC.**

### ➤ **What Should I Wear?**

Attire for Wednesday, Friday and Saturday is casual. Check the weather in Washington, DC ([www.weather.com](http://www.weather.com)) before you leave as the spring weather can change quickly in our Nation’s Capital. For the meetings Thursday on Capitol Hill with Members of Congress, coat and tie is recommended for men and a nice dress or pantsuit is recommended for women. **Wear comfortable shoes.** The halls of Congressional office buildings are made of marble and there are miles of them!

### ➤ **Conference Registration**

Conference registration will begin at 7:00 a.m. Wednesday morning at the JW Marriott and continues until 7:00 p.m. that day. Conference registration will re-open on Thursday morning at 7:00 a.m. and continue until 2:00 p.m., and on Friday morning at 8:00 a.m. until 1:00 p.m. If you are only attending Congressional meetings on Thursday and not participating in any other part of the conference, please contact your Chapter to coordinate your meeting schedule. If you are unsure of which Chapter represents you or have questions about your Congressional meetings, please contact the Public Policy Department using our toll-free Advocacy Day Hotline at 1-877-444-ALSA (2572).

Due to the extraordinary turnout for this Conference and budget constraints, only registered advocates will be able to attend Conference functions. Therefore, please make sure you and others who may be traveling with you are registered to attend the Conference as registration badges will be verified by door monitors when advocates enter Conference functions and sessions.

### ➤ **Leave Behind Packets**

Chapter delegation leaders should check-in at the Congressional Meeting Check-in Desk, which will be located near the Conference registration desk to confirm your Chapter’s Congressional meeting schedule and pick-up your delegation’s leave-behind packets for your Members of Congress. **The Congressional Meeting Check-in Desk will be open on Wednesday afternoon only.** Also, drop your letters off here so we can add them to the Leave Behind Packets and make sure your Chapter gets credit for them.

### ➤ **Transportation During the Conference**

A handicap accessible shuttle bus will run between the JW Marriott and the other official conference hotels throughout the conference. Additional information about the shuttle will be available at the Public Policy Conference registration desk. A sign will also be displayed in the lobby of the hotels outlining the shuttle schedule and details.

- **Thursday, May 9:** Bus transportation will be provided from the JW Marriott to Capitol Hill, starting at approximately 8:30 a.m. Buses to and from the Hill and hotel run throughout the day. **THE LAST BUS**

**WILL LEAVE THE HILL AT 5:30 PM.** If you have a meeting after 5:00 p.m., you must notify the Public Policy Department in advance so other transportation arrangements can be made.

- The Metro System has stops accessible to both the House and Senate sides of Capitol Hill and the hotel. The closest Metro stop to the Senate Office Buildings is Union Station and the closest Metro stop to the House Office Buildings is Capitol South. The closest metro stop to JW Marriott is Metro Center.

➤ **Parking**

For Thursday’s appointments on Capitol Hill, parking is available at the Union Station Parking Garage (202-898-1950) at Union Station on 30 Massachusetts Avenue, NE. The garage is open 24 hours a day and the rates are as follows: \$7.00 for the first hour, \$10.00 for 1-2 hours, \$13.00 for 2-3 hours, \$16.00 for 3-5 hours, \$22.00 for 5-24 hours. The garage has two entrances; the most convenient to the Senate Office Buildings is on Massachusetts Ave, NE, by Columbus Circle. Passenger vehicles higher than 7 feet 5 inches cannot be accommodated by the garage.

➤ **Medical Equipment**

If ALS Advocates need a wheelchair or any additional Durable Medical Equipment (DME) during their visit to Washington, DC for Advocacy Day, they can contact **Roberts Home Medical Company**. For power wheelchairs and scooters, contact Kelly Rullo at (301) 353-0300, ext. 4550 or [krullo@robertshomemedical.com](mailto:krullo@robertshomemedical.com). For manual wheelchairs, Hoyer lifts and other medical equipment, contact Amanda Villanueva at (301) 353-0300, ext. 4123 or [avillanueva@robertshomemedical.com](mailto:avillanueva@robertshomemedical.com).

Advocates may want to consider renting a wheelchair, even if they do not currently use one, as the day on the Hill can involve several trips between buildings and may be very tiring for ALS patients.

➤ **Food on Capitol Hill**

Each delegation is on their own for lunch and we strongly encourage you to stagger your lunch time as the cafeterias will be busy with Hill staff and other groups during the peak lunch times. A Hospitality Room will be open at the JW Marriott from 2:00 p.m. – 6:00 p.m. for advocates to complete meeting reports and de-brief with other advocates about their meetings.

<b><u>Dining in the House Office Buildings</u></b>	<b><u>Dining in the Senate Office Buildings</u></b>
<b>Cannon Carryout Cafeteria</b> Room: B-114 7:30 AM – 4:00 PM	<b>Dirksen North Servery</b> Room: Dirksen Basement, NW corner 7:30 AM – 3:00 PM
<b>Longworth Cafe</b> Room: B-223 7:30 AM -2:30 PM	<b>Dirksen South Buffet</b> Room: Dirksen Basement, South Side 11:30 AM – 2:30 PM
<b>Rayburn Cafeteria</b> Room: B-357 7: 30 AM – 2:30 PM	<b>The Hart Senate Chef</b> Room: Dirksen/Hart Ground Floor Connector 8:00 AM – 6:30 PM
<b>Rayburn Deli</b> Room: B-236 11:00 AM – 7:00 PM	<b>Russell Carry-Out</b> Room: Russell Basement, NW corner 7:30 AM – 5:00 PM

**The Capitol Visitor’s Center**, main entrance at First and East Capitol streets, also has a restaurant. It is located in the lower level of the Visitor Center and is open from 8:30 a. m. to 4:00 p.m.

## ➤ Food Near the JW Marriott Hotel

There are many dining option for advocates attending the Conference. Listed below are options within walking distance or a short taxi ride of the JW Marriott Hotel, the Conference headquarters hotel.

		<u>Area Code: 202</u>
<b><u>American</u></b>		
1331, JW Marriott Hotel	\$\$, Casual, Dinner Daily, Lunch Mon-Fri	Ext. 6610
Avenue Grill, JW Marriott Hotel	\$\$, Casual, Breakfast/Lunch/Dinner Daily	Ext. 6970
Bobby Van's Grill, 1201 New York Ave.	\$\$\$ , Casual, Lunch/Dinner Daily	Ph. 589-1504
Chef Geoff's, 1301 Pennsylvania Ave	\$\$, Casual, Dinner Daily, Lunch Mon-Fri	Ph. 464-4461
Equinox, 818 Connecticut Ave. NW	\$\$\$ , Smart Casual, Lunch Mon-Fri, Dinner Mon- Sat	Ph. 331-8118
Hamilton, 600 14 <sup>th</sup> Street, NW	\$\$, Casual, Breakfast/Lunch/Dinner Daily	Ph. 787-1000
M&S Grill, 600 13 <sup>th</sup> Street	\$\$, Casual, Dinner Daily, Lunch Mon-Fri	Ph. 347-1500
Old Ebbitt Grill, 675 15 <sup>th</sup> Street	\$\$, Casual, Breakfast/Lunch/Dinner Daily	Ph. 347-4800
Occidental Grill, 1475 Penn. Ave, NW	\$\$\$ , Smart Casual, Lunch/Dinner M-S; Din. Sun	Ph. 783-1475
Oval Room, 800 Connecticut Ave. NW	\$\$, Smart Casual, Lunch Mon-Fri, Dinner Mon-Sat	Ph. 463-8700
Woodward Tablet, 1426 H St NW	\$\$, Casual, Dinner, Lunch & Dinner Daily	Ph. 347-5353
<b><u>Asian,Sushi,Thai, Chinese</u></b>		
Chalin's, 1912 I St. (Chineses)	\$\$, Casual, Lunch & Dinner Daily	Ph. 293-6000
Sushi Aoi, 1100 New York Ave	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 408-7770
Haad Thai, 1100 New York Ave.	\$\$, Casual, Dinner Daily, Lunch Mon-Fri	Ph. 682-1111
Kaz Sushi Bistro, 1915 I Street	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 530-5500
SEI, 444 7 <sup>th</sup> St. (Sushi)	\$\$, Casual, Dinner Daily	Ph. 783-7007
<b><u>French/German</u></b>		
Café Mozart, 1331 H Street NW(Germ)	\$\$, Casual, Lunch & Dinner Daily	Ph. 347-5732
Café Du Parc, 1401 Pennsylvania Av.	\$\$, Casual, Breakfast/Lunch/Dinner Daily	Ph. 942-7000
Central, 1001 Penn Ave. NW	\$\$\$ Business Casual, Dinner Daily, Lunch Mon-Fri	Ph. 626-0015
<b><u>Indian</u></b>		
Bombay Club, 815 Connecticut Ave	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 659-3727
<b><u>Italian</u></b>		
Finemondo, 1319 F Street	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 737-3100
Tosca, 1112 F Street	\$\$\$ , Business Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 367-1990
Tuscana West, 1350 I Street	\$\$, Smart Casual, Dinner Mon-Fri, Lunch Mon-Fri	Ph. 289-7300
<b><u>Latin, Caribbean, Brazilian</u></b>		
Fogo de Chao, 1101 Penn. Ave	\$\$\$ , Casual, Lunch (M-F) Dinner (7days a week)	Ph. 347-4668
Ceiba, 701 14 <sup>th</sup> . Street	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 393-3983
<b><u>Southern</u></b>		
Georgia Brown's, 950 15 <sup>th</sup> Street	\$\$, Smart Casual, Dinner Daily, Lunch Mon-Fri	Ph. 393-4499
<b><u>Steakhouse</u></b>		
Bobby Van's, 809 15 <sup>th</sup> . Street	\$\$\$ , Business Casual, Lunch & Dinner Daily	Ph. 589-0060
BLT Steakhouse, 1625 I St. NW	\$\$\$ , Business Casual, Dinner Daily, Lunch Mon-Fri	Ph. 689-8999
Del Frisco's Grill, 1201 Penn. Ave.	\$\$, Smart Casual, Dinner Daily, Lunch Mon-Fri	Ph. 450-4686
Social Reform, 401 9 <sup>th</sup> Street	\$\$\$ , Smart Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 393-1300
Capital Grill, 601 Pennsylvania Ave	\$\$\$ , Business Casual, Dinner Daily, Lunch Mon-Fri	Ph. 737-6200
Ruth's Chris, 724 9 <sup>th</sup> Street NW	\$\$\$ , Smart Casual, Dinner Daily	Ph. 393-4488
<b><u>Seafood</u></b>		
DC Coast, 1401 K Street NW	\$\$, Smart Casual, Lunch Mon-Fri, Dinner Mon-Sat	Ph. 216-5988
McCormick & Schmick, 901 F St.	\$\$, Smart Casual, Dinner Daily, Lunch Mon-Fri	Ph. 639-9330
Legal Seafood, 704 7 <sup>th</sup> St.	\$\$, Smart Casual, Lunch/Dinner Mon-Fri	Ph. 347-0007
<b><u>Breakfast</u></b>		
Corner Bakery, 14 <sup>th</sup> and F St.	\$, Casual, Breakfast/Lunch Daily	Ph. 662-7450
Harry's, 436 11 <sup>th</sup> St.	&&, Casual, Breakfast/Lunch/Dinner Daily	Ph. 624-0053
<b><u>Brewery/Pubs</u></b>		
Capitol City, 11 <sup>th</sup> and H St.	\$\$, Casual, Lunch/Dinner Daily	Ph. 628-2222
Gordon Biersch, 900 F St.	\$\$, Casual, Lunch/Dinner Daily	Ph. 783-5454
Elephant & Castle, 1201 Penn. Ave.	\$\$, Casual, Lunch/Dinner Daily	Ph. 347-7707

\$-Inexpensive\*\*\$\$-Moderate\*\*\*\$\$\$-Mid-Expensive\*\*\$\$\$\$-Expensive

## ➤ **Advocacy Day Letters**

Accompanying this packet is an Advocacy Day letter that you can give to friends or family who are not attending the Conference in Washington. [Click here to download a template of the letter.](#) Please ask them to sign a letter for each of their Senators and then you can personally deliver the letters to Senators when you are on Capitol Hill on Thursday, May 9. In this way, people who cannot join us in Washington, can still tell the ALS story and make a difference

- [Download the template letter.](#) You can view a copy of the letter on the next page.
- Please make a letter for both of your Senators. Just use the template downloaded above and insert the Senator's name and the name of your state before printing the letter.
- If you do not know the name of your Senators enter your zip code on the Advocacy Action Center to identify them: <http://capwiz.com/alsa/home/>
- Please ask advocates who are not attending to sign both letters and include their complete mailing address so the Member knows it is a letter from a constituent and can send a response.
- Please provide signed letters to your Chapter Delegation Leader so that he or she can drop them off at the Congressional Meeting Check-in Desk. The Public Policy Department will make sure they are added to the leave behind packets and make sure your Chapter receives credit for the letters.

The Honorable [Senator's Full Name]  
United States Senate  
Washington, DC 20510

Dear Senator [Senator's Last Name],

I am writing to urge you to work with your colleagues on the Appropriations Committee to appropriate **\$10 million in FY 2014 for the ALS Research Program (ALSRP) at the Department of Defense**. The ALSRP is designed to find a treatment for **Lou Gehrig's Disease**, a disease that **strikes military veterans at approximately twice the rate** as the general public according to studies supported by the NIH, Department of Defense, Department of Veterans Affairs and Harvard University.

Today, **military veterans in [State Name] living with ALS are fighting a war in which they have no way to defend themselves**. As the disease progresses, it robs them of the ability to control their muscles, trapping them in a body they no longer can control. They are isolated and awake, aware of the world around them, yet unable to do anything about it. There is **no effective treatment** for the disease and it is **fatal in just two to five years** after diagnosis. However, the **ALSRP is specifically designed to find a treatment for ALS**.

In fact, **the program fills a gap in the drug development pipeline in which limited funding has prevented promising treatments from reaching patients**. Moreover, the ALSRP provides funding to researchers on a competitive grant basis and **researchers here in [State Name] are eligible to receive funding from the program**.

Congress has appropriated funding for the ALSRP in each of the past five years. However, the FY 2013 funding level of \$7.5 million only will be able to support about four projects even though nearly 150 were submitted in 2012. Therefore, I request that you work with your colleagues to support a \$10 million appropriation in FY 2014 to continue this program, which will benefit our military veterans and all people whose lives have been touched by ALS.

**I hope you will continue to support our troops and your constituents here in [State Name]**. Help us fight for our heroes in the military as they continue their war against ALS.

Sincerely,

\_\_\_\_\_  
Signature

Full Name (print): \_\_\_\_\_

Home Address: \_\_\_\_\_

City, State, Zip Code: \_\_\_\_\_

Email: \_\_\_\_\_

[Click here to download a template](#)

My ALS Story: [INSERT NAME]

[City, State]

(Insert Photo)	(Insert Photo)
Before My Diagnosis	Now

I am a: (insert words to describe you: mom, son, grandparent, teacher, accountant, etc.)

My life changed on (insert dx date), when I was diagnosed with Amyotrophic Lateral Sclerosis, also known as Lou Gehrig's disease. ALS is a particularly cruel disease that destroys a person's ability to control muscle movement. As the disease progresses, I may become trapped inside my body; unable to walk, talk, breathe or even blink an eye.

**There is no effective treatment for ALS, no known cause and no cure.**

The disease also does not discriminate in who it strikes and can impact anyone at anytime, regardless of their age, gender, race or ethnicity. Military veterans are approximately twice as likely to die from ALS as those who have not served in the military.

[If a veteran, insert information about military service here.]

And it is always fatal – in an average of two to five years following diagnosis.

This disease has robbed me from: (insert your ALS story here)

I believe we can find an effective treatment and cure but we need your help to continue the progress we've made over the past few years at CDC and DOD. Please support our 2013 public policy priorities:

- **Appropriate \$10 million to continue the National ALS Registry at the Centers for Disease Control and Prevention.**
- **Appropriate \$10 million to continue the ALS Research Program (ALSRP) at the Department of Defense (DOD).**
- **Cosponsor the MODDERN Cures Act**