



**National Advocacy Day and
Public Policy Conference**

Schedule at a Glance

**2015 National ALS Advocacy Day and Public Policy Conference
May 10-12, 2015**

JW Marriott

1331 Pennsylvania Avenue, NW, Washington, DC 20004

Phone: (202) 393-2000

Sunday, May 10

9:00 am – 8:00 pm	Registration Open at the JW Marriott
12:00 pm – 8:30 pm	ALS Marketplace Open
3:30 pm – 4:30 pm	Welcome Remarks/Opening Session
4:30 pm – 4:45 pm	Refreshment Break
4:45 pm – 5:30 pm	Prep for the Hill
6:30 pm – 8:15 pm	Mother's Day BBQ
8:30 pm – 9:00 pm	Candlelight Tribute at Freedom Plaza
9:30 pm – 11:00 pm	Ice Cream Social

Monday, May 11

8:00 am - 4:00 pm	Registration Desk Open
8:00 am – 5:30 pm	ALS Marketplace Open
8:00 am – 9:00 am	Continental Breakfast
9:15 am – 10:30 am	The State of ALS Research
10:30 am – 11:00 am	Refreshment Break
11:00 am – 12:30 pm	Government ALS Research
12:30 pm – 1:15 pm	Meet the Researchers
1:15 pm – 2:30 pm	Luncheon
2:30 pm – 4:30 pm	Chapter Strategy Sessions
4:45 pm – 5:45 pm	Public Policy Question & Answer Session
	Dinner on your own

Tuesday, May 12

7:30 am – 9:00 am	Celebration of Excellence 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)
3:00 pm – 6:00 pm	Hospitality Room Open at JW Marriott Hotel
5:30 pm	Last Bus Departs from Capitol Hill



The ALS Association's 2015 Public Policy Priorities

- **Continue appropriations for critical ALS research programs at the Centers for Disease Control and Prevention and Department of Defense (DOD).**

- 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 the National ALS 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 nine years. 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 2016 to continue the registry, fund registry-related ALS research, help people with ALS enroll in the registry, conduct outreach activities to identify ALS cases across the country, establish an ALS 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. 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, the current level leaves more than 95% of submitted projects unfunded. 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. 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 Dormant Therapies Act**

Regulatory barriers and limited incentives to pursue innovation have hindered the development of new treatments 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.

The Dormant Therapies Act 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 that can improve, prolong and, ultimately, save lives. Specifically the bill will: Encourage research on treatments that hold promise for treating diseases with unmet medical needs, but have been set aside in the lab because they lack or have weak patents.

- **Ensure Access to Speech Generating Devices: Enact the Steve Gleason Act**

The Centers for Medicare and Medicaid Services (CMS) has taken several different actions that deny people with ALS timely access to the speech generating devices (SGDs) that meet their specific medical needs. These actions fundamentally change long-standing coverage policy and significantly limit what technologies are available to people with ALS. Specifically, CMS has:

- Issued a “coverage reminder” that would prohibit coverage for SGDs that include non-speech technologies such as email, internet access and environmental controls;
- Routinely begun to deny coverage for eye tracking, which is needed in order to access SGDs by people who have lost mobility ; and
- Implemented a "capped rental" payment system that requires people with ALS to first rent SGDs for a period of 13 months before owning the device. If a person is admitted to hospice, a hospital or a nursing facility during the rental period, Medicare payment for the SGD will cease. Moreover, people with ALS may not “unlock” SGDs during the rental period, which denies them access to non-speech technologies.

The ALS Association has been working with CMS, Members of Congress and other stakeholders for nearly a year to fight these policies, including securing the signatures of 200 Members of Congress on a letter to CMS expressing concerns about SGD policy. CMS has since rescinded the “coverage reminder” and is reconsidering its SGD coverage policy, a process expected to continue until July 31, 2015. However, action is needed to address the challenges created by the capped rental payment system and denials of coverage for eye tracking technology. The Steve Gleason Act would eliminate the capped rental requirement, which will allow people with ALS to unlock SGDs and access non-speech technologies. The legislation also helps assure coverage for eye tracking and would enable people to keep SGDs when they transfer to hospice, a hospital or nursing facility.

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 official satellite hotels outlining the shuttle schedule.

Marriott at Metro Center

775 12th Street, NW
Washington, DC 20005
Phone: 202-737-2200

Marriott Residence Inn

1199 Vermont Avenue, NW
Washington, DC 20005
Phone: 202-898-1100

➤ Ground Transportation to the Hotel

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

Taxi Depending on such factors as traffic, the number of passengers and luggage, cab fare will cost approximately \$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 13th 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 \$40. For reservations, visit www.supershuttle.com or call 800-BLUE-VAN.

From Dulles International Airport (about 27 miles from the hotels)

Taxi Depending on such factors as traffic and the number of passengers, cab fare will cost approximately \$65 (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 \$70. For reservations, visit www.supershuttle.com or call 800-BLUE-VAN.

From Baltimore/Washington International Airport (about 40 miles from the hotels)

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 \$88. For reservations, visit www.supershuttle.com or call 800-BLUE-VAN.

From Washington's Union Station (train station)

Two taxi companies provide wheelchair-accessible transportation from Union Station:

Royal Taxi For reservations, call 202-398-0500 or visit www.dctaxionline.com (Note: Be sure to select "Wheelchair accessible" at the top)

Yellow Taxi For reservations, call 202-544-1213 or visit www.dcyellowcab.com (Note: request a wheelchair accessible cab by selecting the Add Special Options drop down menu)

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 adaroom@alsa-national.org 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 Jason Harris at (202) 465-8805.

➤ **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 you.

During the "Prep for the Hill" session, which takes place on Sunday, May 10 from 4:45 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 Monday afternoon to prepare for your meetings on Tuesday.

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.**
- **ALS Story Telling Exercise:** Included in your confirmation email is a link to download a template you can use to help tell your ALS story ([click here to download template](#)). This worksheet allows you to craft a personal story that translates the impact of ALS and public policy on the lives of actual people.
- **Ask your friends, family and other patients who are not attending the Conference to sign the letter to Congress** that is included at the end of the confirmation packet or [download it here](#). 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 on the ballroom level at the JW Marriott Hotel. The Public Policy Department tracks the number of letters each Chapter brings with them to the Conference. You will need to return to the Check-In Desk to collect your letters before it closes at 5:30 on Monday, so you are able to deliver them during your meetings.
- **Gather material from your Chapter or Support Group** to take on your visits (e.g. brochure, business card, list of Board Members, 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.)
- **Take pictures of your meeting** for your Chapter's newsletter, website and to use on your social media accounts.
- **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 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**

You will be able to access your Congressional meeting schedule on your iPhone, iPad, Android and Blackberry! The “Advocacy Days” app by Constituent Voice can be found in the Android Market and the Apple App Store. **You will receive instructions on from your delegation leader during the working session on how to log into your meeting schedule, but be sure to download the app prior to coming to DC.** If you attended the conference last year and used the app, it is recommended that you uninstall it and then download the app again to make sure it works correctly.

➤ **What Should I Wear?**

Attire for Sunday and Monday is casual. Check the weather in Washington, DC (www.weather.com) before you leave as the spring weather can change quickly in our Nation’s Capital. For the meetings Tuesday 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 9:00 am Sunday morning at the JW Marriott and continues until 8:00 pm that day. Conference registration will re-open on Monday morning at 8:00 am and continue until 4:00 pm. If you are only attending Congressional meetings on Tuesday 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 will receive your delegation’s leave-behind packets prior to the start of the conference. Please stop by the Congressional Meeting Check-in Desk, which will be located near the ALS Marketplace, for any meeting schedule updates and to drop-off/pick-up your delegation’s Senate letters. **The Congressional Meeting Check-in Desk will be open Sunday afternoon and Monday only.**

➤ **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.

- **Tuesday, May 12:** Bus transportation will be provided from the JW Marriott to Capitol Hill, starting at approximately 8:30 am. 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 pm, 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 (Red line) and the closest Metro stop to the House Office Buildings is Capitol South (Blue and Orange lines). The closest metro stop to JW Marriott is Metro Center (Blue, Orange and Red lines).

➤ **Parking**

For Tuesday’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, \$9.00 for 1-2 hours, \$10.00 for 2-4 hours, \$13.00 for 3-5 hours, and \$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 wheelchairs, scooters and hoier lifts: contact Daryl Horton, dhorton@robertshomemedical.com, or (301) 353-0300, ext. 4585. For hospital beds: contact Meagan McNeely, mmcneely@robertshomemedical.com, or (301) 353-0300, ext. 4009

Loaner equipment will not be available at the hotel. 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. The company will deliver the equipment to your hotel before the conference starts and will pick it up from the hotel after the conference ends.

Please note: if you are renting a hospital bed or if you will be using a hoier lift, please notify Mary Wisniewski at adaroom@alsa-national.org, as the hotel must be made aware in advance of your stay.

➤ **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 3:00 pm – 6:00 pm for advocates to complete meeting reports and de-brief with other advocates about their meetings. 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 am to 4:00 pm.

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

➤ Food Near the JW Marriott Hotel

		<u>Area Code: 202</u>
<u>American</u>		
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
Del Frisco's, 1201 Pennsylvania Ave. NW	\$\$, Casual, Lunch Mon-Fri, Dinner Mon- Sat	Ph. 331-8118
Equinox, 818 Connecticut Ave. NW	\$\$\$, Smart Casual, Lunch Mon-Fri, Dinner Daily	Ph. 331-8118
Hamilton, 600 14 th Street, NW	\$\$, Casual, Breakfast/Lunch/Dinner Daily	Ph. 787-1000
Old Ebbitt Grill, 675 15 th 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
Joe's Seafood Prime Steak, 750 15 th St.	\$\$\$, Smart Casual, Dinner Daily	Ph. 489-0140
Woodward Tablet, 1426 H St NW	\$\$, Casual, Dinner, Lunch & Dinner Daily	Ph. 347-5353
<u>Asian,Sushi,Thai, Chinese</u>		
Asia Nine, 915 E St, NW	\$\$, Casual, Lunch & Dinner Daily	Ph. 629-4355
Chalin's, 1912 I St. (Chinese)	\$\$, 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 th St. (Sushi)	\$\$, Casual, Dinner Daily	Ph. 783-7007
<u>French/German</u>		
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
<u>Indian</u>		
Bombay Club, 815 Connecticut Ave	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 659-3727
<u>Italian</u>		
Finemondo, 1319 F Street	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 737-3100
Fiola, 601 Pennsylvania Ave.	\$\$\$, Smart Casual, Lunch & Dinner Mon-Fri	Ph. 628-2888
Siroc, 915 15 th St.	\$\$, Smart Casual, Lunch Mon-Fri, Dinner Daily	Ph. 628-2220
Tosca, 1112 F Street	\$\$\$, Business Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 367-1990
<u>Latin, Caribbean, Brazilian</u>		
Fogo de Chao, 1101 Penn. Ave	\$\$\$, Casual, Lunch (M-F) Dinner (7days a week)	Ph. 347-4668
Ceiba, 701 14 th . Street	\$\$, Casual, Dinner Mon-Sat, Lunch Mon-Fri	Ph. 393-3983
<u>Southern</u>		
Georgia Brown's, 950 15 th Street	\$\$, Smart Casual, Dinner Daily, Lunch Mon-Fri	Ph. 393-4499
<u>Steakhouse</u>		
Bobby Van's, 809 15 th . 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
Capital Grill, 601 Pennsylvania Ave	\$\$\$, Business Casual, Dinner Daily, Lunch Mon-Fri	Ph. 737-6200
J&G Steakhouse, 515 15 th St, NW	\$\$\$, Business Casual, Lunch & Dinner Daily	Ph. 661-2400
Ruth's Chris, 724 9 th Street NW	\$\$\$, Smart Casual, Dinner Daily	Ph. 393-4488
<u>Seafood</u>		
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 th St.	\$\$, Smart Casual, Lunch/Dinner Mon-Fri	Ph. 347-0007
<u>Breakfast</u>		
Corner Bakery, 14 th and F St.	\$, Casual, Breakfast/Lunch Daily	Ph. 662-7450
Harry's, 436 11 th St.	&&, Casual, Breakfast/Lunch/Dinner Daily	Ph. 624-0053
<u>Brewery/Pubs</u>		
Capitol City, 11 th 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

May 12, 2015

Dear Senator,

On April 1, 2014, the Centers for Medicare and Medicaid Services (CMS) changed the manner in which it pays for speech generating devices (SGDs) and in the process took away the voices of thousands of people living with Lou Gehrig's disease who rely on SGDs to communicate.

As you may know, ALS is a fatal neurological disease that robs people of the ability to control their muscles. They lose the ability to walk, use their hands and arms and ultimately the ability to breathe. The disease is fatal in an average of two to five years following diagnosis and there is no effective treatment available to slow or stop its progression. As the disease progresses, people often lose the ability to speak and therefore rely on SGDs for all of their communications needs. SGDs become a person's window to the world. Without it, they are isolated and awake, trapped inside a body they cannot control and unable to communicate even a single word.

Under the change implemented by CMS in April 2014, called "capped rental," people with ALS who need SGDs will be required to rent them over a 13-month period, after which time they will own the device. Under the previous policy, people with ALS had the option to purchase SGDs up front, which is how over 99% of them obtained SGDs. While this switch may seem to be a minor change in policy, it may have significant impacts on patients. Those impacts include:

- Access: If people have an extended hospital stay, are in hospice or a nursing facility while they are in the 13-month rental period, Medicare will not cover the rental fees. Instead, the device must be returned to the manufacturer while the patient either will have to obtain a new one from the hospital, hospice or nursing facility, or pay the entire monthly rental fee out-of-pocket. This will result in patients losing access to SGDs while they are institutionalized, during a time when their health is at the highest risk and when the devices are most needed to communicate with medical staff. These institutions and facilities do not have access to SGDs, are not funded to supply the devices and do not typically have staff experienced in providing SGDs. In addition, because SGDs are highly customized devices, designed and adjusted to meet the specific medical needs of each individual patient, they cannot readily be substituted with "off the shelf" technology.
- Cost: People who rent SGDs for the full 13-month rental period will pay 5% more out-of-pocket than if they had purchased the device up front.

The ALS Association is working with Members of Congress to oppose this regulation and give a voice to people with ALS. I urge you to work with The Association in this fight. ALS robs people of so many things that most people take for granted. Please work with us to ensure that CMS polices do not also rob people of the ability to communicate. Please contact The ALS Association at advocacy@alsa-national.org if you would like to join this fight in support of your constituents living with ALS.

Sincerely,

Name: _____

Street Address: _____

City, State, Zip: _____

Email: _____