



TESTIMONY FOR THE ENERGY AND COMMERCE COMMITTEE

SUBCOMMITTEE: HEALTH

EXAMINING BIPARTISAN LEGISLATION TO IMPROVE THE MEDICARE PROGRAM

JULY 20, 2017

THE ALS ASSOCIATION

The ALS Association strongly supports passage of the *Steve Gleason Enduring Voices Act of 2017 (H.R.2465)* and appreciates the opportunity to submit testimony to the Energy and Commerce Committee on this bill. The legislation, named for Steve Gleason, a NFL star with the New Orleans Saints and activist living with ALS, is critical to individuals who require speech generating devices. The bill will make permanent the protections achieved in the *Steve Gleason Act of 2015* including ensuring that patients can retain their personal speech generating devices in all healthcare setting and that “effective use” of the devices includes critical eye-gaze coverage.

Amyotrophic Lateral Sclerosis (ALS) is a neurological disease that causes severe muscle weakness resulting in disability and death. There is no known cause or cure for ALS. This disease is complex and variable with an average life expectancy of two to five years from the time of diagnosis. Those who have served in the military are twice as likely to be diagnosed with ALS. For people living with ALS – as well as people with other medically complex conditions - speech generating devices (SGDs) are the primary means they have to communicate with their loved ones and express their health care and personal needs

SGDs are systems used to supplement or replace speech or writing for individuals whose cognitive function and need for communication remains intact, but the physiological ability to speak diminishes. Speech generating devices are the only effective communication means for these people living with these conditions, offering greater control of their health and their lives. SGDs are durable and customizable medically-purposed technologies that allow the person living with ALS, along with their caregiver or speech-language pathologist, to utilize vocabulary, language and accessibility options to meet the unique changing needs of their situation. The patient’s need for an alternative communication system is most critical in an institutionalized setting because of the need for effective communication with healthcare staff.

When access to SGDs in all care settings (including nursing homes) was threatened, the ALS Community worked with Team Gleason, the American Speech-Language and Hearing Association and advocates in the field to protect access to these vital devices, which resulted in the passage of the *Steve Gleason Act of 2015* which will expire on October 1, 2018.



Our Vision
Create a world without ALS.
Our Mission

To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

In response, a bipartisan bill, *the Steve Gleason Enduring Voices Act of 2017* (H.R. 2465), has been introduced by Representatives Cathy McMorris Rodgers (WA-5) and John B. Larson (CT-1) and has already gained support from 66 other Representatives. A companion bill has been introduced in the Senate (S. 1132) by Senators Bill Cassidy (LA) and Sen. Amy Klobuchar (MN).

This legislation's passage would make the changes that were implemented by the *Steve Gleason Act of 2015* permanent including maintaining the payment category for these personalized devices, letting people keep their SGDs in all care settings (including nursing homes) and providing coverage for the accessories needed to allow for the devices to work effectively.

The ALS Association thanks the Energy and Commerce Committee for including this bill in today's hearing and strongly urges Congress to support and pass the *Steve Gleason Enduring Voices Act of 2017* this year to ensure that there is no break in access. The passage of this legislation will ensure that Medicare's most vulnerable patients have access to SGDs and related accessories in all healthcare settings. People living with ALS and other unstable and degenerative diseases deserve the peace-of-mind that their ability to communicate will not be taken away from them when they enter a healthcare facility.

The ALS Association looks forward to working with Congress in a bipartisan fashion on this and other issues critical to those living with ALS and their families. The ALS Association is the only national non-profit fighting ALS on every front by fostering public and private research, providing care support for people with ALS through a nationwide network of chapters, coordinating multidisciplinary healthcare through certified care centers and promoting public policies to improve the lives of people with ALS and their families.

For further information on this and other legislation of importance to people living with ALS and their families, please contact Kathleen Sheehan, Vice President for Public Policy, The ALS Association at ksheehan@alsa-national.org/(202) 464-4684 or visit our website at www.alsa.org.