



May 3, 2017

Honorable Kevin Brady, Chair
House Committee on Ways and Means
1102 Longworth House Office Building
Washington, D.C. 20515

Honorable Orrin Hatch, Chair
Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, D.C. 2051

Honorable Greg Walden, Chair
House Committee on Energy and Commerce
2121 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Hatch, Chairman Brady and Chairman Walden,

The ALS Association, on behalf of people living with ALS, strongly endorses and urges you to support the Steve Gleason Enduring Voices Act of 2017 championed by Representatives Cathy McMorris Rodgers and John Larson along with Senators Bill Cassidy M.D. and Amy Klobuchar. The ALS Association fights to cure ALS and to improve care for people living with ALS by leading the way in global research, providing assistance for people with ALS through a national network of chapters, coordinating multidisciplinary care through certified clinical care centers, and much more.

The ALS Association supports this legislation because it would make permanent the Steve Gleason Act of 2015, which ensures that Medicare beneficiaries are able to keep their speech generating devices (SGD) when they are admitted into a hospital, hospice, or nursing facility. The 2017 bill would remove a sunset provision of October 1, 2018 under the existing law.

Amyotrophic Lateral Sclerosis (ALS) is a neurological disease that causes severe muscle weakness resulting in disability and death. There is no effective treatment, no known cause, and no cure for ALS. This disease is complex and variable with an average life expectancy of two to five years from the time of diagnosis. For people living with ALS – as well as people with multiple sclerosis, Parkinson’s disease, paralysis and other debilitating conditions – speech generating devices are one of the primary means they have to communicate with their loved ones, as well as express their health care and personal needs.

We urge you to support and pass the Steve Gleason Enduring Voices Act of 2017 to remove the sunset date as soon as possible, ensuring that Medicare’s most vulnerable patients have access to SGDs and related accessories. These patients deserve the peace-of-mind that their ability to communicate will not be taken away from them when they need it most.

Sincerely,

A handwritten signature in black ink that reads "Barbara Newhouse". The signature is written in a cursive, flowing style.

Barbara Newhouse, President and CEO

Cc: Rep. Pat Tiberi, Chair Ways and Means Subcommittee on Health, Rep. Michael Burgess, Chair, Energy and Commerce Subcommittee on Health

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