April 28, 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. 20510

Dear Chairman Brady and Chairman Hatch:

The under-signed 82 organizations and professionals urge you to support the Steve Gleason Enduring Voices Act of 2017 to revise the Steve Gleason Act of 2015 (114th Congress S. 984). The Steve Gleason Enduring Voices Act will remove the sunset date, currently identified in law as October 1, 2018. We seek this revision to prevent extremely vulnerable Medicare beneficiaries from ever again having to relinquish their only means of communication. By revising the Steve Gleason Act of 2015 to remove the sunset date, beneficiaries with ALS, MS, Parkinson’s disease, paralysis, cerebral palsy and other debilitating conditions will be assured that Medicare coverage for speech generating devices (SGD) and related accessories will continue to be available.

In the six months immediately prior to the effective date of the Steve Gleason Act (April 1, 2015 to September 30, 2015), SGDs, which are uniquely configured for each user, were covered by Medicare via a capped rental payment category. Under CMS rules, if an SGD user resided for more than a brief period of time in a nursing home, hospice or hospital, Medicare payment for the SGD stopped. Confusion and harm ensued. Nursing homes, hospice programs and hospitals did not and could not supply beneficiaries with a uniquely configured SGD substitute. These most vulnerable individuals had to go without SGDs, leaving them unable to communicate. Some died without being able to say goodbye.

Section 3 of the Steve Gleason Act of 2015 removed the rental cap for durable medical equipment under Medicare for a three year period with respect to speech generating devices. In pertinent part, it moved SGDs to a Medicare payment category and it amended Section 1834(a)(2)(A) of the Social Security Act (42 U.S.C. 1395m(a)(2)(A)(3)(iv) as follows, “in the case of devices furnished on or after October 1, 2015, and before October 1, 2018, which serves as a speech generating device or which is an accessory that is needed for the individual to effectively utilize such a device.”

Ongoing and permanent access to Medicare coverage for SGDs would ensure individuals who medically qualify for an SGD would be able to continue communicating, even if they had to leave home to live in a nursing facility, hospice or hospital. Allowing this provision of the Steve Gleason Act of 2015 to expire would create substantial access barriers for those who use SGDs and who are in nursing facilities, hospice or hospitals – at a time when the need for communication with providers and caregivers is critical.

It is only eighteen months away from the sunset date; individuals throughout the country, who have no other means of speaking, worry that the law will expire. We therefore urge you to support and pass the Steve Gleason Enduring Voices Act of 2017 to remove the expiration date as soon as possible, ensuring that Medicare’s most vulnerable beneficiaries can have access to SGDs and related accessories. These individuals deserve the peace-of-mind that their ability to communicate will not be wrested away from them.

If you have questions or need additional information, please contact Kathy Holt at the Center for Medicare Advocacy KHolt@MedicareAdvocacy.org or (202) 293-5760.

Sincerely,



Steve Gleason

and

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| Academy of Spinal Cord Injury Professionals |
| ACCSES |
| Aging Life Care Association |
| Alliance for Retired Americans |
| ALS Association |
| ALS of Michigan |
| American Association on Health & Disability |
| American Congress of Rehabilitation Medicine |
| American Council of the Blind |
| American Occupational Therapy Association |
| American Society on Aging |
| American Speech-Language Hearing Association |
| American Therapeutic Recreation Association |
| Answer ALS Foundation |
| Assistive Technology Industry Association |
| Assistive Technology Law Center  |
| Association of Assistive Technology |
| Association of University Centers on Disabilities |
| Autistic Self Advocacy Network |
| Brain Injury Association of America |
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| California Health Advocates |
| Center for Medicare Advocacy |
| Cerebral Palsy Association of Nassau County |
| Cerebral Palsy Associations of New York State  |
| Christopher and Dana Reeve Foundation |
| Clinician Task Force |
| Colorado Cross-Disability Coalition |
| Compassionate Care ALS |
| Disability Law Project of Vermont Legal Aid |
| Disability Policy Consortium of Massachusetts |
| Disability Rights Oregon |
| Easterseals |
| Girl Power 2 Cure |
| Justice in Aging |
| Lakeshore Foundation |
| Legal Council for Health Justice |
| Long Term Care Community Coalition  |
| Medicare Rights Center |
| National Association for Home Care and Hospice  |
| National Association of Elder Law Attorneys |
| National Association of State Head Injury Administrators |
| National Coalition for Assistive and Rehab Technology |
| National Committee to Preserve Social Security and Medicare |
| National Consumer Voice for Quality Long-Term Care |
| National Disability Rights Network |
| National Health Law Program  |
| National MS Society |
| Northwest Health Law Advocates |
| Not Dead Yet |
| Perkins School for the Blind |
| Public Justice Center, Baltimore, Maryland |
| Rehabilitation Engineering and Assistive Technology Society  |
| Smartbox |
| Southern Disability Law Center |
| Special Needs Alliance |
| Talk To Me Technologies |
| Team Gleason |
| The ARC of the United States |
| The Michael J. Fox Foundation for Parkinson's Research |
| Tobii DynaVox |
| United Cerebral Palsy |
| United Spinal Association  |
| United States Society for Augmentative and Alternative Communication |
| Volunteers of Legal Service |
| Women's Institute for a Secure Retirement Professionals:

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