

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."

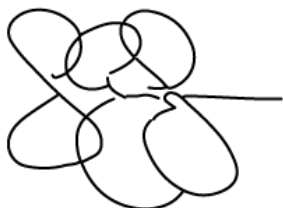
Ongoing and permanent access to Medicare coverage for SGDs would ensure individuals who medically qualify for an SGD would be able to continue communicating, even if they had to leave home to live in a nursing facility, hospice or hospital. Allowing this provision of the Steve Gleason Act of 2015 to 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,

A handwritten signature in black ink, consisting of several overlapping loops and a horizontal line extending to the right.

Steve Gleason

and

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

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

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