



May 24, 2017

**SUBMITTED ELECTRONICALLY**

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

Honorable Richard Neal, Ranking Member  
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

Honorable Ron Wyden, Ranking Member  
Senate Committee on Finance  
219 Dirksen Senate Office Building  
Washington, D.C. 20510

**Re: Support for Medicare Beneficiary Access to Speech Generating Devices and Eye Tracking Accessories**

Dear Chairman Brady, Ranking Member Neal, Chairman Hatch, and Ranking Member Wyden,

The undersigned members of the Independence through Enhancement of Medicare and Medicaid (“ITEM”) Coalition urge you to support the Steve Gleason Enduring Voices Act of 2017, S.1132 and H.R. 2465, to revise the Steve Gleason Act of 2015 (114<sup>th</sup> Congress S. 984). The Steve Gleason Enduring Voices Act will remove the sunset date, currently identified in law as October 1, 2018, of Public Law 114-40. We seek this revision to prevent vulnerable Medicare beneficiaries from ever again having to relinquish their only means of communication. Speech-generating devices (SGDs) are highly customized electronic augmentative and alternative communication (AAC) systems used to supplement or replace speech, enabling individuals with functional communication needs to communicate verbally. By revising the Steve Gleason Act of 2015 to remove the sunset date, speech generating devices and related accessories will continue to be available for Medicare beneficiaries with ALS, MS, Parkinson’s disease, paralysis, cerebral palsy and other debilitating conditions.

The original Steve Gleason Act was enacted effective October 2015 and corrected some significant limitations in access to appropriate technology impacting some of the most vulnerable Medicare beneficiaries. Significant policy re-interpretation by the Centers for Medicare & Medicaid Services (CMS) in 2013 had resulted in the reclassification of SGDs to capped-rental items. These requirements prohibited patients from personalizing their SGDs during the 13-month rental period, and did not allow standard “upgrades,” such as internet or email access. It was difficult to comprehend this policy since these devices are customized and most SGD

recipients, due to their chronic and degenerative conditions, continue to have severe speech deficits well beyond the 13-month timeframe.

As a result of additional policy misinterpretation regarding the technology capabilities of the devices, CMS contractors were routinely denying coverage for “eye-gaze” technology on an SGD for individuals with limited or no mobility in their arms and hands. The result of these denials has been to severely limit some beneficiaries’ access to communication devices.

Although CMS has some regulatory authority to resolve some SGD problems, CMS indicated that the capped-rental issue must be addressed through legislation. The Steve Gleason Act of 2015 (PL 114-40) resolved this issue by removing the rental cap for durable medical equipment under Medicare for a three-year period with respect to SGDs, ensuring that beneficiaries have access to necessary eye-tracking accessories for these devices. However, the law currently faces an October 1, 2018 sunset date that, if unchanged, will significantly impact access to these essential technologies for Medicare beneficiaries.

As a result, individuals throughout the country, who have no other means of expressing speech, 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 sunset date as soon as possible, ensuring that some of 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 sunset along with the law.

The ITEM Coalition supports S. 1132 and H.R. 2465, the Steve Gleason Enduring Voices Act of 2017. We hope that this important legislation will be passed swiftly by Congress and enacted into law.

We thank you for your continued efforts to resolve this Medicare access issue by removing the capped-rental requirement for speech-generating devices and ensuring that beneficiaries have access to necessary eye-tracking accessories for these devices.

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The ITEM Coalition is a national consumer and clinician-led coalition advocating for access to and coverage of assistive devices, technologies, and related services for persons with injuries, illnesses, disabilities, and chronic conditions of all ages. Our members represent individuals with a wide range of disabling conditions, as well as the providers who serve them, including such conditions as multiple sclerosis, spinal cord injuries, brain injuries, stroke, paralysis, limb loss, cerebral palsy, hearing and speech impairments, visual impairments, vision loss, spina bifida, myositis, and other life-altering conditions.

We greatly appreciate your attention to this important issue. Should you have further questions regarding the information contained in our letter, please contact Leif Brierley, ITEM Coalition staff, via email at [Leif.Brierley@PowersLaw.com](mailto:Leif.Brierley@PowersLaw.com) or by calling 202-466-6550.

Sincerely,

**ITEM Coalition Steering Committee**  
American Foundation for the Blind

Amputee Coalition  
Christopher and Dana Reeve Foundation  
National Multiple Sclerosis Society  
Paralyzed Veterans of America  
United Spinal Association

**Undersigned Members of the ITEM Coalition**

Academy of Spinal Cord Injury Professionals  
ACCSES  
American Association on Health and Disability  
American Cochlear Implant Alliance  
American Congress of Rehabilitation Medicine  
American Foundation for the Blind  
American Occupational Therapy Association  
American Speech-Language-Hearing Association  
American Therapeutic Recreation Association  
Amputee Coalition  
Assistive Technology Industry Association  
Association for Education and Rehabilitation of the Blind and Visually Impaired (AER)  
Association of Assistive Technology Act Programs  
Brain Injury Association of America  
Caregiver Action Network  
Center for Medicare Advocacy  
Christopher and Dana Reeve Foundation  
Clinician Task Force  
Lakeshore Foundation  
National Association for the Advancement of Orthotics and Prosthetics  
National Disability Rights Network  
National Multiple Sclerosis Society  
Paralyzed Veterans of America  
Rehabilitation Engineering and Assistive Technology Society of North America  
Spina Bifida Association  
The Arc of the United States  
The Myositis Association  
Unite 2 Fight Paralysis  
United Cerebral Palsy  
United Spinal Association