

March 26, 2014
The Honorable Senator Franken
309 Hart Senate Office Building
Washington DC 20510

Dear Senator Franken,

I am a veteran of the U.S. Navy living in Minnesota with ALS (Lou Gehrig's disease). Today, I am writing you to express concern about new Medicaid and Medicare rules that will have a pronounced negative effect on the lives of those living with ALS and other debilitating diseases. Additionally, I want to urge your support of the bi-partisan legislation introduced as S. 948 and HR 942.

Below, I include the eloquent letter written by ex-NFL player and ALS patient and advocate Steve Gleason to his Louisiana Congress delegation. Mr. Gleason writes and speaks using technology that the new Medicaid and Medicare rules will no longer provide to those who need it:

Recently, legislation was introduced to ensure patient access to quality, complex rehabilitation technology. An example of that technology is my power chair. I cannot imagine living with ALS (or any other physically restrictive disease) without a power chair. It is not only a necessity, it is a means of independence for me and my caregivers. The bi-partisan legislation introduced is S. 948 and HR 942. While every organization that supports the care of people with physical limitations supports this, not one legislator from Louisiana has signed it as of today.

Adding to this, the Centers for Medicare & Medicaid Services (CMMS) have new rules which become effective April 1st. Exactly the opposite of the legislation above, these superfluous rules will inhibit people from having consistent access to essential communication devices. The term essential is not hyperbole. I use my eyes to type on one of these devices. Essential communication; from requests for food or water, to telling my family I love them, advocating at the United Nations, or open letters to policy makers.

While I am very fortunate to have the ability to own and customize my equipment, most people who are dealing with ALS, and conditions like ALS, do not. Living with a physically debilitating disease is not only a tremendous emotional burden, but a financial one as well. By taking away access to these devices, the CMMS is harming the very people the institution was created to help.

Imagine if your cell phone, tablet and laptop were taken away when you had a hospital visit. While it is logical to rent "simple" machines like a car or a pressure washer for periods at a time, renting complex and customizable technology like a cell phone, tablet or laptop is far less viable, especially when that technology is your only means of connecting to the world.

I was recently in a Microsoft commercial. The commercial shows how transformative technology has been to individuals and the world. Microsoft calls these technologies "empowering". These new rules from the CMMS will quash the power that technology gives people like me... people who intend to be productive and purposeful.

Please sign S 948 and HR 942. And, please introduce immediately an exclusion for Speech Generating Devices (SGDs). Thank you for your attention to this important issue and for your voice in Washington, DC. Through your support, you will also safeguard the voices of thousands of others.

Steve Gleason

Please support this legislation and work to provide an exclusion for Speech Generating Devices (SGDs) in the Medicaid and Medicare rules.

Sincerely,
Steve Bachman
XXXX Virginia Avenue
Shoreview, Minnesota 55126
651-XXX-XXXX