ALS Association
Fighting Lou Gehrig's Disease

The Amyotrophic
Lateral Sclerosis
Association

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September 24, 2007

The Honorable Tom Allen
U.S. House of Representatives
Washington, DC 20515

The Honorable Ron Lewis
U.S. House of Representatives
Washington, DC 20515

Dear Representatives Allen and Lewis:

I am writing on behalf of The ALS Association and the thousands of people with ALS we serve across the country to express our strong support for H.R. 2231, the "Medicare Access to Complex Rehabilitation and Assistive Technology Act." Your leadership in introducing this important legislation is vital to ensuring that people with ALS continue to have access to complex power wheelchairs, which play a critical role in the lives of all people living with this horrific disease.

The ALS Association and our more than 40 Chapters and affiliates across the country represent people living with amyotrophic lateral sclerosis (ALS), their families, and caregivers. As the only national voluntary health association dedicated solely to the fight against ALS, The Association works to support people with ALS every day. Our goals are to improve the quality of life for those living with the disease and to discover a treatment and cure.

As you know, ALS, more commonly known as Lou Gehrig's disease, is a progressive, fatal, neurodegenerative disease that erodes a person's ability to control muscle movement. The average life expectancy for people with ALS is two to five years following diagnosis and there is no known cause, cure or means of prevention for the disease. Currently, only one drug has been approved by the FDA to treat ALS, but that drug has shown only limited affects, prolonging life by just a few months. However, advances in technology, particularly the availability of complex power wheelchairs, have enabled people with ALS to continue to live productive lives as they fight the debilitating affects of the disease.

The ALS Association is concerned that changes in Medicare coverage and reimbursement policies, such as Medicare's competitive acquisition program,

The ALS Association is the only national not-for-profit voluntary health organization whose sole mission is to find a cure for and improve living with ALS.

Member National Health Council

may inappropriately restrict patient access to the quality health care that the Medicare program was created to deliver. We are particularly concerned with how this new program may impact the availability of the highly customized, complex power wheelchairs on which people with ALS desperately need to complete the daily activities that most of us take for granted.

People who have lost the ability to stand, walk, use their arms and hands, and even breathe on their own require the use of wheelchairs that are far more advanced than those typically needed by most Medicare beneficiaries. Indeed, the complex chairs required by people with ALS are highly customized so that they can respond to their unique medical needs. Unfortunately, the competitive acquisition program as currently proposed does not recognize the complexities of ALS, the difficulties imposed by the disease, or the sophisticated equipment and services that are required to improve the lives of people with ALS and their families.

While we applaud Congress and the Centers for Medicare and Medicaid Services for working to reduce costs and combat fraud and abuse, these efforts must not be accomplished in a manner that is detrimental to beneficiaries, like people with ALS, who are among the most vulnerable Medicare patients.

That is why we are pleased to endorse H.R. 2231. By exempting only those complex technologies needed by people with ALS and other serious conditions, the bill preserves patient access to needed technologies and recognizes that one-size-fits-all policies are not always appropriate when it comes to ALS.

On behalf of the people with ALS and their families we serve, The ALS Association applauds your leadership on this important issue and your commitment to our cause. We look forward to working with you and your colleagues to enact H.R. 2231 this session.

Sincerely,

Steve Gibson

Steve Gibson
Vice President, Government Relations and Public Affairs