ALS
ASSOCIATION

A Reason for Hope

The Amyotrophic
Lateral Sclerosis
Association

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Dear Member of Congress:

I am writing on behalf of The ALS Association to express our strong opposition to legislation that would eliminate the noninterference provision of the Medicare Modernization Act (MMA). Legislation that authorizes the federal government to negotiate Medicare prescription drug prices will significantly limit the ability of people with ALS to access the drugs they need and will seriously jeopardize the future development of treatments for the disease – a disease that is always fatal and for which there currently are no effective treatment options.

The ALS Association is the only national voluntary health organization dedicated solely to finding a treatment and cure for amyotrophic lateral sclerosis (ALS). More commonly known as Lou Gehrig's disease, ALS is a progressive neurodegenerative disease that erodes a person's ability to control muscle movement. As the disease advances, people lose the ability to walk, move their arms, talk and even breathe, yet their minds remain sharp; aware of the limitations ALS has imposed on their lives, but powerless to do anything about it. They become trapped inside a body they no longer can control.

There is no cure for ALS. In fact, it is fatal within an average of two to five years from the time of diagnosis. Moreover, there currently is only one drug available to treat the disease. Unfortunately, that drug, Rilutek, originally approved by the FDA in 1995 has shown only limited effects, prolonging life in some patients by just a few months.

The hopes of people with ALS – those living today and those yet to be diagnosed – are that medical science will develop and make available new treatments for the disease; treatments that will improve and save their lives.

However, The ALS Association is deeply concerned that the elimination of the MMA's noninterference provision will dampen these hopes and will result in unintended consequences for the thousands of Americans fighting this horrific disease. The potential impacts are significant and include:

Limits on Innovation

While reducing the cost of prescription drugs is an important goal, it should not be done at the expense of innovation. Unfortunately, eliminating the MMA's noninterference provision will limit the resources available to develop new breakthrough medicines. This is especially troubling for a disease like ALS, for the development of new drugs offers patients their best, and likely only, hope for an effective treatment.

Additionally, by establishing price controls, Congress will undermine the incentives it has established to encourage drug development in orphan diseases, like ALS. As resources available for research and development become more scarce, there will be even less incentive to invest in orphan drug development.

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

Limits on Access

The elimination of the noninterference provision will have particularly cruel consequences for people with ALS. It means that even if a new drug is developed to treat ALS, many patients likely will not have access to it. That's because price controls can limit access to the latest technologies. Proponents of government negotiated prices cite the Department of Veterans Affairs as a model for how the government should negotiate prices for Medicare prescription drugs. Yet under that system, patients do not have access to many of the latest breakthrough treatments. For example, two of the most recently developed drugs to treat Parkinson's and Multiple Sclerosis, neurological diseases like ALS, are not covered by the VA due to the government negotiated price. Ironically, those drugs currently are covered by Medicare Part D.

Given this scenario, we are deeply concerned that any new drug that is developed for ALS will not be available to the vast majority of patients who need it. Instead they either will be forced to forgo treatment, or only will have access to less effective treatment options – ones that may add a few months to their lives, but not ones that will add years or even save their lives.

People with ALS Rely on Medicare

A significant percentage of people with ALS rely on Medicare, and the newly established prescription drug benefit, to obtain their health and prescription coverage. In fact Congress recognized the importance of Medicare coverage for people with ALS by passing legislation to eliminate the 24-month Medicare waiting period for people disabled with the disease. This law helps to ensure patients have timely access to the health care they need. With the establishment of the Part D benefit, Congress also has now helped to ensure that people with ALS have access to coverage for vital prescription drugs.

Yet this improved access is threatened by short-sighted and inappropriately cost driven efforts to remove the noninterference provision. If Congress makes this change, they will undo what the MMA sought to ensure: access to needed prescription drugs.

While The ALS Association appreciates attempts to improve access to affordable prescription drugs, we believe that Congress must consider the implications of its actions on coverage, access and the advancement of medical science. We fear that in an effort to control costs, Congress may limit treatment options, discourage innovation, and extinguish the hopes of thousands of Americans whose lives have been touched by ALS and who are fighting to find a treatment and cure. On behalf of your constituents living with Lou Gehrig's disease, we urge you to oppose legislation to eliminate the noninterference provisions of the Medicare Modernization Act.

Sincerely,

Steve Gibson

Steve Gibson,
Vice President, Government Relations and Public Affairs