

March 30, 2023

The Honorable Senator Donna Bailey
The Honorable Representative Anne Perry
Committee on Health Coverage, Insurance and Financial Services

Re: Support for LD1165 An Act to Enhance Cost Savings to Consumers of Prescriptions Drugs

Dear, Chair Bailey, Chair Perry and members of the committee,

On behalf of all ALS patients, including the 33 patients we serve in Maine, I respectfully request your support for LD 1165, which will require Pharmacy Benefit Manager (PBM) rebates to be passed through to patients at the point of sale

Amyotrophic lateral sclerosis (ALS), or ‘Lou Gehrig’s’, is a fatal progressive neurodegenerative disease that slowly robs a person’s ability to walk, talk, eat, and eventually breathe. The cost of care for someone living with ALS is astronomical, with annual out-of-pocket expenses reaching over \$80,000 per year. As with many people living with complex medical conditions, those with ALS must take various drugs to maintain their health. The out-of-pocket costs associated with prescription drugs significantly add to this crushing financial burden.

As ALS progresses, most people lose their ability to work and can be terminated from their jobs due to their inability to perform to perform tasks. If the person with ALS is the primary working in the family - who provides health care coverage for their spouse and children, everyone in the family is left without a health insurance plan. While the person with ALS may be able to get Medicare if they are eligible for Social Security Disability, what they receive is not sufficient, and they still need to purchase Medicare supplemental coverage and pay for any out of pockets costs for Medicare.

If there is a working spouse, that person can often become a working caregiver or may have to quit their job to provide the care services. Family members must hope they can get coverage through the ACA health exchanges or go on Medicaid. While losing insurance may be one of the first financial burdens a person with ALS faces following their diagnosis, it is certainly not the last. Patients may lose their ability to pay for their house, food, and medical cost coverage – all of which impacts their families.

Under the current insurance system, volume-based manufacturer rebates on pharmaceutical drugs are negotiated by PBMs in exchange for formulary placement. Instead of passing these savings through to patients who desperately need to afford their prescriptions, these rebates are retained by the PBMs and health insurers. This means that our most vulnerable citizens – those living with complex conditions like ALS, do not benefit from the lower net price of their lifesaving and life sustaining medications and pay far more than they should.

With rebates for branded drugs averaging 48%, patients are paying nearly twice what their insurance company pays for the same drug. Sadly, when patients cannot afford their medications, they may ration or abandon their prescribed therapy, leading to painful and costly complications, or more tragic outcomes, worsening quality of life and driving up overall health care costs.

The ALS Association supports ending the current practice of overcharging consumers through health plans in an effort to reduce the financial toll ALS takes on patients.

Thank you for your time and your consideration of this critical legislation. For all these reasons, we respectfully request your support for LD1165.

Sincerely,

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