



Written Testimony on Behalf of The ALS Association

RE: Support for HB177 - Prohibit certain health insurance cost-sharing practices

Submitted: October 9, 2023

Thank you for the opportunity to offer written testimony in support of HB177, “Prohibit certain health insurance cost-sharing practices.” My name is Lindsay Gill, and I am the Managing Director of Advocacy for the mid-Atlantic region for The ALS Association. I am submitting testimony today to emphasize the urgent need for reform in our healthcare system to protect vulnerable Ohioans, particularly those battling ALS and other rare and chronic diseases.

Over the past decade, the landscape of healthcare finance has evolved in ways that have disproportionately burdened patients with chronic illnesses, such as ALS. Insurance companies and pharmacy benefit managers (PBMs) have increasingly imposed higher deductibles and copayments (the amounts that people with health insurance must pay when they receive health care). For many people with chronic illnesses, the cost-sharing requirements for medications they need to survive have become insurmountable, even with insurance coverage. As a result, patients increasingly must rely on financial assistance from charitable foundations and drug manufacturers.

Unfortunately, health plans and PBMs are actively undermining this lifeline of support through the use of “copay accumulator adjustment policies” or “CAAPs.” These immoral policies allow

insurers and PBMs to profit at the expense of patients by failing to count the financial assistance provided by manufacturers towards enrollees' annual deductible and out-of-pocket limits. This unjust practice effectively allows insurers to “double-dip” and get paid twice by pocketing the third-party assistance payments and forcing patients to keep paying exorbitant amounts for lifesaving and life-sustaining medications, despite their eligibility for assistance.

Just last week, Judge John B. Yates of the U.S. District Court for the District of Columbia, [struck down](#) a previously enacted rule that allowed health plans and PBMs to collect funds from both patients and drugmakers while not using any of that money to alleviate the financial burden on patients. With this development, we are hopeful that Ohio can take a stand against these cruel practices by passing HB177 and protect vulnerable Ohioans from further exploitation.

It is crucial to understand the gravity of this issue in the context of ALS, a progressive, always fatal, disease that mercilessly robs people of their ability to walk, talk, eat and eventually breathe. There are just six FDA-approved treatments. Relyvrio, for example, has an astonishing cost of \$158,000 per year with no generic or less expensive alternative. Amylyx, the manufacturer, offers a prescription assistance program for eligible patients who have commercial insurance, effectively eliminating their co-pay. Without this discount program, Ohioans living with ALS can face prescription costs of \$1,000 to \$4,000 per month for just one drug. ALS patients often require a variety of medications to deal with the complications that come with the disease (and for unrelated comorbidities), driving the annual costs of treatment, care, supports, and services to as high as \$250,000.

Our healthcare system certainly has its share of challenges, but the truth remains that unfair coverage policies are exacerbating the hardships faced by vulnerable patients. These patients find themselves at risk of deteriorating health and compromised treatment outcomes when they can no longer afford their medications or are forced to ration their prescriptions to make ends meet. The moment a patient learns that financial assistance is no longer accepted by their insurer or counted toward their deductible, often at the pharmacy counter, it can unleash immense disruption and stress in their life, affecting not only them but also loved ones and care providers.

In conclusion, HB177 offers a lifeline to Ohioans in dire need of life-saving treatments by mandating that *all payments* made by or on behalf of a patient count toward their cost-sharing obligations. I implore you to lend your support to this bill, to protect the most vulnerable among us, and to rectify the unfettered profiteering in our healthcare system.

I welcome any follow-up questions or continued dialogue on this crucial matter. Thank you for your time and consideration.

Thank you,

Lindsay Gill

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