

March 26, 2024

House Health and Government Operations Committee

**SB 595 – Health Benefit Plans - Calculation of Cost Sharing Contribution - Requirements and Prohibitions**

**Position: SUPPORT**

Dear Chair Pena-Melnyk, Vice Chair Cullison, and Honorable House Health and Government Operations Committee Members,

On behalf of all ALS patients, **I respectfully request your support for SB 595**, which will significantly help reduce the out-of-pocket healthcare costs for our community. **I also write in strong opposition to the current version of HB 879.**

Amyotrophic lateral sclerosis (ALS) 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 upwards of \$250,000 per year. As with many people living with complex medical conditions, those with ALS must take various drugs to maintain their health. The copays associated with acquiring them significantly add to this crushing financial burden.

One way that patients afford their care is through copay assistance programs, where cards or coupons from nonprofit organizations or drug manufacturers help reduce the cost of drugs. However, insurers and pharmacy benefit managers increasingly use copay accumulator adjustment programs to prevent such assistance from counting towards patient cost-sharing, such as their deductible or annual out-of-pocket maximum.

Copay accumulator adjustment programs do not just harm patients' pocketbooks; they undermine their access to life-saving prescription drugs, making it even more difficult for people living with ALS and other complex medical conditions to adhere to a treatment plan. With lower copays, consumers are less likely to skip taking their medications.

We strongly support the prohibition of copay accumulator adjustment programs. We believe that all patients should be able to afford necessary treatments by ensuring all payments – made by or on behalf of the patients – are counted towards a patients' deductible and out-of-pocket maximums.

Thank you for your time and your consideration of this critical legislation. For all these reasons, we respectfully request your support for SB 595

Sincerely,



OUR VISION: Create a world without ALS.

OUR MISSION: To discover treatments and a cure for ALS, and to serve, advocate for, and empower people affected by ALS to live their lives to the fullest.

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