RARE READY
A GENETIC CONDITION COALITION

June 11, 2025

The Honorable Joe Lombardo
Governor, State of Nevada
State Capitol Building
101 N. Carson Street
Carson City, NV 89701

RE: Veto AB 259

Dear Governor Lombardo:

The Rare & Ready Coalition strongly opposes AB 259 and respectfully requests your veto. This bill would attempt to set caps on the price paid for prescription drugs in Nevada based on the “maximum fair price” (MFP) negotiated by the federal Medicare program.

Rare & Ready is a coalition of 80 non-profit organizations working to ensure rare disease patients get timely access to the care they need and deserve. We are alarmed by the devastating impact MFP caps will have on patient access to life-saving therapies.

We strongly urge you to consider the unique circumstances of rare disease patients and therapies as this bill awaits your signature. In 2023, you vetoed a nearly identical bill (AB 250) from the same sponsor. Your veto message echoed our concerns, stating “caps could restrict patients’ access to medicines and result in less innovative treatments for patients.” We thank you for your previous support and encourage you to continue protecting access for patients living with a rare disease, who have no treatment alternatives. It’s critical you consider the real-world experiences of those living with or caring for someone with a rare disease here in Nevada.

Patients living with rare diseases often have limited treatment options with 95 percent of such conditions lacking any FDA-approved therapies. State efforts to arbitrarily set price caps on existing treatments, while intended to make drugs more affordable for health plans, would deter access to the critical medical innovations available for people living with rare diseases – many of whom are children.

“Maximum fair price” seeks to cap prescription drug reimbursement for certain health plans in the state. However, rather than fostering cost savings and enhancing patient affordability, the outcome of a price cap is an environment where access to innovative therapies is restricted.

This unfortunate reality will predominantly impact rare disease patients. Maximum fair price is untested and doesn’t consider issues within the broader pharmaceutical supply chain, such as the role of pharmacy benefit managers (PBMs) and the application of significant rebates and discounts that fail to benefit patients directly.

While we share the goal of reducing costs for patients, AB 259 raises significant concerns:

1. Potential Limitations on Access: “Maximum fair price” may prevent insurers and pharmacies from purchasing medications exceeding government-set prices, reducing treatment options for patients.

2. Crippling Innovation and Jeopardizing Patients' Health: When the government imposes mandates on the private sector, there are always unintended consequences that only hurt consumers. In this case, price controls discourage innovation, making it impossible for companies to develop rare disease treatments. As a result, rare disease patients who depend on groundbreaking therapies will be the ones that suffer.

AB 259 will not lower prescription drug costs for Nevada residents. Applying the Medicare MFP does not guarantee patients will realize any of the savings from the lower list price. There is no mechanism for the Nevada Division of Insurance to ensure that state-regulated plans alter their cost-sharing designs for drugs with MFPs nor does the Division have the authority to regulate large-group and self-funded plans governed by federal ERISA law. Price caps do not lower patient copayments, reduce premiums, create health system transparency, or increase access to care for rare patients. The reality is price caps result in less rare disease research, fewer new treatments for patients, and restricted patient access to medicines.

For these reasons, we respectfully request your veto of AB 259 and urge you to consider its dipropionate impact on people living with rare diseases in Nevada.

Sincerely,

Rare & Ready Coalition Members