RARE READY
A GENETIC CONDITION COALITION

February 4, 2025

The Honorable Pamela Beidle, Chair
Senate Committee on Finance
Miller Senate Office Building, 3 East Wing
11 Bladen St., Annapolis, MD 21401 – 1991

Dear Chair Beidle and Members of the Committee:

The Rare & Ready Coalition would like to express our opposition to SB 357, a bill to expand the scope of the Maryland Prescription Drug Affordability Board (PDAB). Rare & Ready is a coalition of 70 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 the existing PDAB and its potential expansion will have on patient access to life-saving therapies.

We strongly urge the Committee to consider the unique circumstances of rare disease patients and therapies as it considers this legislation. You must protect 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.

Patients living with rare and genetic disorders often have limited treatment options, with 95 percent of such conditions lacking any FDA-approved therapies. State efforts to create PDABs, while intended to make drugs more affordable for health plans, can deter access to critical medical innovations. The implications are most profound for patients living with a rare disease, many of whom are children.

PDABs are unelected boards set up by state legislators to cap prescription drug reimbursement for certain health plans in the state. Rather than fostering cost savings and enhancing patient affordability, the outcome of a PDAB is an environment where access to innovative therapies is restricted. This unfortunate reality will predominantly impact rare disease patients.

While we share the goal of reducing costs for patients, SB 357 raises significant concerns:

1. Potential Limitations on Access: The bill's "Upper Payment Limits" 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

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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.

SB 357 will do nothing to lower prescription drug costs for Maryland residents. PDABs do not lower patient copayments, reduce premiums, create health system transparency, or increase access to care for rare patients. The reality is PDAB reimbursement caps result in less rare disease research, fewer new treatments for patients, and restricted patient access to medicines.

Additionally, the bill does not adequately address 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.

For these reasons, we respectfully express our opposition to SB 357 in its current form and urge you and your colleagues in the Maryland Legislature to consider its dipropionate impact on people with rare and genetic disorders.

We urge the committee to hear directly from rare disease patients and the parents of children battling these conditions before making any decisions. This legislation is not just about dollars—it carries life-altering consequences for the most vulnerable among us. Please take the time to understand their stories before moving forward. We welcome the opportunity to connect you to those who are directly impacted—please reach out to the coalition administrator at kari.lato@rx4good.com to schedule a meeting with your constituents.

Sincerely,

Rare & Ready Coalition Members