March 24th, 2026

The Rhode Island Legislature
Senate Committee on Health and Human Services
Rhode Island State House
82 Smith Street
Providence, RI 02903

Re: SB 2253 An Act Relating to Insurance

On behalf of the EveryLife Foundation for Rare Diseases, we are pleased to submit testimony in support of SB 2253. The EveryLife Foundation for Rare Diseases is powered by the rare disease community to improve health outcomes by driving change through evidence-based policy, leading science-driven policy and regulatory research, activating the community to advocate for their rights and needs, and strengthening the rare disease community. SB 2253 requires insurers and pharmacy benefit managers in Rhode Island to include third-party payments toward enrollees' out-of-pocket maximums and cost sharing for prescription drugs, taking effect for health plans starting January 1, 2027.

It is estimated that over 30 million Americans live with one or more rare diseases that often result in burdensome medical, indirect, and non-medical expenses.[1] Patients and families must navigate how to manage expenses from multiple inpatient and outpatient encounters, costs for prescription therapies and medical devices, and the support services that are critical for managing their health and well-being.

While 95% of rare diseases do not yet have an FDA-approved treatment,[2] for those patients who do have an available therapy, cost-sharing assistance from drug manufacturers and patient assistance programs is an important factor in the ability to access life-altering and life-saving treatments. Unfortunately, insurance companies are increasingly employing copay adjustment programs that prevent cost-sharing assistance from being applied to a patient's deductible or out-of-pocket maximum, removing the lifeline of cost-sharing assistance programs. SB 2253 would prevent insurers from using these programs to take advantage of Rhode Island residents.

While copay adjustment programs can reduce costs for insurance companies, they leave patients with unexpected and unaffordable costs once their copay assistance is exhausted. In 2022, the EveryLife Foundation published The National Economic Burden of Rare Diseases in the United States, a study that examined the comprehensive economic impact of a subset of 379 rare diseases. The study found that the total economic impact of rare diseases in the US in 2019 was

[1] National Human Genome Research Institute. (2019, March 9). *Rare Diseases FAQ*. Genome.gov. https://www.genome.gov/FAQ/Rare-Diseases
[2] Gürkan, H., & Satkın, N. B. (2025). The importance of genetic diagnosis in rare diseases. *Balkan Medical Journal*, *42*(2), 92–93. https://doi.org/10.4274/balkanmedj.galenos.2025.2025-270125

$997 billion; 60% of those costs were indirect and non-medical costs shouldered directly by families and society. Of the direct costs, inpatient care was the top driver of medical costs (~15%) while prescription medication was responsible for about 11% of medical costs.[3] With the proliferation of high-deductible health plans, copay adjustment programs result in higher out-of-pocket costs for the frequent expert outpatient care that rare disease patients require as it takes longer for patients to satisfy the deductible and out-of-pocket maximum requirements.

Copay adjustment programs eat into the already tight budget patients have, forcing some patients to take harmful actions, such as medicine rationing and prescription abandonment. An analysis by IQVIA showed that when patient costs reach $250, over 70% of new patients walk away from the pharmacy empty-handed, highlighting the direct connection between the rise in out-of-pocket costs and prescription abandonment.[4] Prescription abandonment is not an option for rare disease patients who are forced to incur considerable financial strain to maintain their prescription medicine costs.

Lowering the costs of health care is an important goal; however, insurance companies that use copay adjustment programs simply shift costs to patients while ultimately collecting up to double the amount of the patient's out-of-pocket requirements. Further exacerbating the tremendous out-of-pocket financial load families living with rare diseases are expected to bear.

Thank you again for the opportunity to testify in support of SB 2253. We are excited at the prospect of Rhode Island joining the 25 states that have enacted similar legislation to protect patient access to treatments by preventing copay adjustment programs.[5] Thank you for ensuring that all Rhode Island residents with a rare disease can maintain access to affordable, life-sustaining medical care.

Sincerely,

Dylan Simon

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EveryLife Foundation for Rare Diseases

Kathryn Poe

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[3] EveryLife Foundation for Rare Diseases. April 2022. The National Economic Burden of Rare Disease in the United States in 2019.
[4] IQVIA. May 2019. Medicine Use and Spending in the US; A Review of 2018 outlook to 2023.
[5] All Copays Count Coalition (2025). State Legislation Against CoPay Accumulators. Can be found at: https://allcopayscount.org/state-legislation-against-copay-accumulators/

CC: Michael Pearlmutter, Chief Executive Officer, EveryLife Foundation for Rare Diseases; Annie Kennedy, Chief Mission Officer, EveryLife Foundation for Rare Diseases; Amy Gaviglio, Chair, Board of Directors, EveryLife Foundation for Rare Diseases