

March 26, 2018

The Honorable Joshua Miller, Chair
The Honorable Gayle Goldin, Vice Chair
Senate Health and Human Services Committee
82 Smith Street
Providence, RI 02903

Dear Chairman Miller, Vice-Chair Goldin, and members of the Committee:

We are writing on behalf of the hundreds of thousands of chronic disease community members, our organizations collectively represent nationally and in Rhode Island, to ask you and your colleagues to oppose S2532. If passed into law, this legislation could prevent the value of copay assistance from being applied towards Rhode Islanders' accumulated out-of-pocket expenses.

With the recent trends in insurance design aimed at shifting more and more of the cost burden onto patients, this bill could have far reaching consequences to those living with chronic and rare diseases in Rhode Island who rely on these programs as the only way to access needed life-saving treatments.

Drug prices can be an arbitrary term to families and individuals living with chronic conditions; instead they realize the cost of medications in premiums, deductibles, copays, and coinsurance. Your constituents' out of pocket costs are determined by Pharmacy Benefit Managers (PBMs) and insurance companies' selection of preferred drugs that enhance their bottom line. If a Rhode Island child or adult with a complex chronic disease wants to remain stable on the same medication, they are forced to meet the demands of fluctuating out of pocket costs with dramatic changes to formularies. Many manufacturers address the burden of out of pocket spending on patients by providing copay assistance coupons. These allow consumers with complex conditions to remain stable on the therapy prescribed by their care providers. The manufacturer takes responsibility for much of the out of pocket cost set by the insurance provider or PBM.

We understand that copay assistance programs can be inappropriately implemented without proper safeguards in place. This poses a risk to the vitality of future programs for those who are most vulnerable. As such, the undersigned organizations support the use of precision copay assistance programs as outlined in a white paper produced by the Global Health Living Foundation (GHLF) and the University of Michigan Center for Value-Based Insurance Design.¹ Rhode Island's Medicare program already sets this precedent by allowing copay accumulator programs provided they are needs based and run through third party non profit organizations. We encourage Rhode Island to further this needs based, patient focused approach to copay assistance programs.

Before attempting to apply a one size fits all approach to this legislation, it is important to consider that high deductible health plan offerings (HDHP's), co-insurance and high tiered formulary placement for high value specialty medications are what precipitated the need for these copay assistance programs. While ideally people would have different plan options to choose from, more often than not their only choice is a HDHP. Now, copay assistance programs have become the only means for many patients to access their life saving therapies. Typically, Rhode Islanders are able to offset the out of pocket costs associated with their deductibles while using copay assistance programs, ensuring that when their coupons run out they are still able to access their treatment without exorbitant copayments. This enables patients to plan for their medical expenses, maintain their prescribed therapies, and stay in control of their health.

Senate Bill 2532 would prevent manufacturer copayment assistance from counting toward a person's out of pocket maximum. This would result in Rhode Island families and/or individuals suddenly being confronted with significant out of pocket costs midway through the plan year, when manufacturer coupons typically run out. This unexpected burden can lead to a decrease in medication adherence, increase prescription abandonment rates, and would ultimately result in poor health outcomes, as evidenced by a large literature review that analyzed over 160 abstracts and publications on patient adherence trends with higher cost sharing.ⁱⁱ

Even the Pharmacy Benefit Management Institute conceded this point,ⁱⁱⁱ "Plan sponsors must develop effective strategies beyond higher cost-sharing for managing specialty drug spend, given the detrimental effect that further copay increases for specialty drugs are likely to have on medication adherence."

People living with chronic conditions such as cancer, rheumatoid arthritis, epilepsy and chronic pain already face barriers to treatment options as the result of insurer cost-saving protocols. Many branded manufacturers currently provide significant rebates and discounts to payers to the tune of nearly \$60 billion in 2015^{iv}. Often, these savings are not passed on to the enrollee. When allowing Insurance providers to restrict copay assistance programs, it enables them to "double dip" by collecting money from both rebates and through high out of pocket costs imposed on patients. For many, non-adherence has the real possibility to produce unintended consequences (i.e. increased ER visits, hospitalizations, long term health issues, and even death)^{v,vi} resulting in much higher costs to the payer than the perceived 'savings' from this cost sharing shift.

As it stands, no state or federal legislation exists to mandate copay accumulator programs like S2532 would. This is because the benefit provided by allowing Americans to use copay assistance programs is clear. Insurance companies still receive necessary payments while those with chronic health conditions are able to access their treatments and retain autonomy over their healthcare spending. The undersigned organizations urge you, on behalf of our Rhode Island community members, to consider the needs of your constituents who rely on copay assistance programs to access their needed medications and withhold support for Senate Bill 2532.

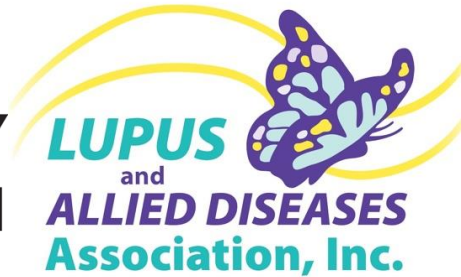
Thank you for your consideration,

Brain Injury Association of Rhode Island
Epilepsy Foundation of New England
Global Healthy Living Foundation
HeartBrothers Foundation
Lupus and Allied Diseases Association, Inc.
Mended Hearts
Mended Little Hearts
National Hemophilia Foundation
National Infusion Centers Association
National Organization of Rare Disorders
New England Hemophilia Association
Patients Rising
SickCells
US Pain Foundation





**EPILEPSY
FOUNDATION**
New England



ⁱ Precision Patient Assistance Programs to Enhance Access to Clinically Indicated Therapies: Right Drug, Right Time, Right Cost-Share. (n.d.). from <http://vbidcenter.org/precision-patient-assistance-programs-to-enhance-access-to-clinically-indicated-therapies-right-drug-right-time-right-cost-share/>

ⁱⁱ How Patient Cost-Sharing Trends Affect Adherence and Outcomes

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3278192/>

ⁱⁱⁱ Pharmacy Benefit Management Institute 2012–2013 Prescription Drug Benefit Cost + Plan Design Report

^{iv} Berkley Research Group. The Pharmaceutical Supply Chain: Gross Drug Expenditures Realized by Stakeholders. 2017.

^v Tarantino MD, Ye X, Bergstrom F, Skorija K, Luo MP. The impact of the economic downturn and health care reform on treatment decisions for haemophilia A: patient caregiver and health care provider perspectives. *Haemophilia*. 2013;19(1):51-58. doi: 10.1111/hae.12008

^{vii} Zhou ZY, Koerper MA, Johnson KA, et al. Burden of illness: direct and indirect costs among persons with hemophilia A in the United States. *J Med Econ*. 2015;18(6):457-465. doi: 10.3111/13696998.2015.1016228