



March 9, 2016

Sen. Joseph J. Crisco, Chairman
Joint Committee on Insurance
LOB Room 2800
Hartford, CT 06106

Rep. Robert W. Megna, Chairman
Joint Committee on Insurance
LOB Room 2800
Hartford, CT 06106

Re: Support for HB 5517

Dear Chairman Crisco, Chairman Megna, and Members of the Committee:

The National Organization for Rare Disorders (NORD) respectfully requests the committee to consider HB 5517, an Act concerning cost sharing for prescription drugs. This bill has the potential to benefit many of our organization's members and their patient communities, as it ensures health plans do not place burdensome cost sharing restrictions on patients that prevent them from obtaining their prescribed medication.

The Danbury-based NORD is the leading voice of the rare disease community dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Any disease affecting fewer than 200,000 Americans is considered rare. We believe strongly that every patient deserves access to the medical care that is prescribed by their doctor and most likely to give them the best clinical outcomes.

The use of higher cost tiers within a drug formulary adversely affects patients with rare diseases because orphan products cost more to develop, and thus can be more expensive, than their non-orphan counterparts. For example, a number of orphan drugs cost \$300,000 or more per year. If placed on a formulary tier with no out-of-pocket limit, these drugs could cost the patient over \$100,000. As a result, unrestricted out-of-pocket costs limit patient access to medically necessary drugs and biologics, as well as target the sickest and most isolated individuals.

HB 5517 will protect patients by prohibiting insurance plans (except for high-deductible health plans) from imposing any cost-sharing that exceeds \$100 for a 30-day supply for a covered prescription drug or place all drugs in a given class on the highest cost-sharing tier in a tiered formulary. This is a feasible real-world solution that can protect vulnerable patients without disrupting plan design and costs.

In 2015, The Leukemia & Lymphoma Society commissioned an analysis of how these proposed changes would impact patients cost-sharing, plan premiums, and actuarial value (AV) compliance. Using plans available in the 2015 health insurance marketplace, an actuarial firm, Milliman, found that these policy changes would dramatically improve affordability



for patients and could be implemented with minimal impact on premiums and AV compliance.¹

Thank you for the opportunity to comment on this legislation. If we can supply additional information, please do not hesitate to let us know. Tim Boyd, NORD's Associate Director of State Policy, is available to assist as needed. Tim can be reached at (202) 545-3830 or via email at tboyd@rarediseases.org.

Sincerely,

Peter L. Saltonstall, President and CEO

CC: Members of the Joint Committee on Insurance and Real Estate

¹ Pharmacy Cost Sharing Limits for Individual Exchange Benefit Plans: Actuarial Considerations.” Milliman, Inc. March 5, 2015. <http://www.ils.org/content/nationalcontent/pdf/ways/Milliman-Report-on-Prescription-Cost-Sharing-Limits-for-Exchange-Plans.pdf>