



October 20, 2016

Honorable Donald White, Chair  
Banking and Insurance Committee  
Senate of Pennsylvania  
286 Main Capitol  
Harrisburg, PA 17120

**Re: Support for SB 841**

Dear Chairman White and Members of the Banking and Insurance Committee:

The National Organization for Rare Disorders (NORD) respectfully requests the committee to consider SB 841, an Act providing requirements for insurers relating to prescription drug coverage. 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.

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.

SB 841, sponsored by Sen. Bob Mensch, will protect patients by prohibiting insurance 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. What's more, according a recent actuarial analysis by Milliman, Inc., changes like the ones proposed by this bill can be implemented within minimal impact on plan design and costs.<sup>1</sup>

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

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



State Policy, is available to assist as needed. Tim can be reached at (202) 545-3830 or via email at [tboyd@rarediseases.org](mailto:tboyd@rarediseases.org).

Sincerely,

A handwritten signature in black ink, appearing to read "Peter L. Saltonstall", is centered within a light gray rectangular box.

Peter L. Saltonstall, President and CEO