



June 8, 2018

The Honorable John F. McKeon
Chair, Committee on Financial Institutions and Insurance
221 Main Street
Madison, NJ 07940

Dear Chairman McKeon:

On behalf of the 1-in-10 New Jersey residents with one of the 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to support A2431, bipartisan legislation to limit out-of-pocket prescription costs.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD believes strongly that every patient deserves the medical care that is best suited for their medical situation and that will give them the best results.

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 patients over \$100,000. As a result, unrestricted out-of-pocket costs limit patient access to medically necessary treatment and target the sickest individuals.

S1865, sponsored by Assemblyman Daniel Benson, Assemblywoman Angelica Jimenez, and Assemblywoman Betty Lou DeCroce, will protect patients by prohibiting insurance plans from imposing any cost-sharing that exceeds \$100 for a 30-day supply of a covered prescription drug (or \$200 for a Bronze plan). According to a 2015 actuarial analysis by Milliman, Inc., changes like the ones proposed by this legislation can be implemented with minimal impact on plan design and cost.¹

In addition, this legislation would create a process that would allow enrollees to request that a nonformulary drug be covered under the formulary if the prescribing physician determines that the already existing formulary drug for the disease in question would not be as effective, would have adverse effects, or both.

In order to guarantee patient safety and help patients avoid financial ruin, New Jersey needs to ensure that out-of-pocket costs do not inappropriately impede access to care. By

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>



implementing the protections created in A2431, the Committee would be protecting patients while still enabling insurers to maintain the integrity of their plan designs and costs.

Thank you for the opportunity to comment on A2431. If NORD can supply additional information, please do not hesitate to let us know.

Sincerely,

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