



May 13, 2019

Sen. Napoleon Harris III, Chairman  
Senate Committee on Insurance  
212 Capitol  
Springfield, IL 62706

**Re: NORD Support for HB 2174**

Dear Chairman Harris and Members of the Senate Committee on Insurance,

On behalf of the approximately 1 in 10 individuals living with a rare disease in Illinois, the National Organization for Rare Disorders (NORD) urges the Committee to support HB 2174, a bill to create consumer protections that ensure that patients living with chronic and life-threatening conditions have affordable, predictable out-of-pocket costs for the treatments they need.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Since 1983, we have been committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD recognizes that the high cost of drugs has a direct impact on patient access. Addressing this and other barriers to care is a priority for our organization. Further, we acknowledge the immense pressure that payors are under to control costs for the sake of all beneficiaries. Yet we do not believe that attempts to address rising costs should come at the detriment of patients. Failing to support patients today, who are in need of immediate assistance to pay for their prescribed treatment, could have a devastating impact on their health.

The use of higher cost tiers within a drug formulary adversely affects patients with rare diseases because most treatments for rare diseases are placed on the highest cost "specialty tier" of an insurance plan drug formulary, which means they are subject to high cost sharing that can be upwards of 50% of the actual cost of the medication. This requirement burdens many people with rare diseases or their caregivers with substantial monthly out-of-pocket costs. Ultimately, these costs can limit patient access to medically necessary drugs, and has the effect of targeting the sickest and most isolated individuals.

HB 2174 will protect patients by applying the following requirements to state-regulated individual and group insurance plans:

- Each carrier must ensure that a pre-deductible copay is applied to the entire prescription drug benefit in at least 25% of individual and group plans offered in each service area and on each metal tier.



- This copay-only benefit design must be reasonably graduated and proportionately related across all tiers of the plan's formulary.
- If a carrier offers only one plan in a given metal level within a service area, that one plan must meet the requirements described above.
- Insurers must annually report changes made during the plan year to their formulary that would adversely impact consumers. These include moving a drug to a higher cost-sharing tier, removing a drug from the formulary or applying additional utilization management controls to a drug during the plan year.

People who rely on regular access to prescription drugs need to understand exactly what their OOP costs will be for the drugs they need each month. By ensuring the availability of copay-only plans, patients will know the precise dollar amount they would have to pay for their medications and can factor that into their household budget for the months ahead.

Again, NORD urges your support for the important consumer protections outlined in this bill which will ensure that patients are able to have affordable, predictable out-of-pocket costs for the treatments they need.

If you have any questions, please contact me at [tboyd@rarediseases.org](mailto:tboyd@rarediseases.org). Thank you in advance for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Tim Boyd".

Tim Boyd, MPH  
Director of State Policy

A handwritten signature in blue ink that reads "Maria Bellefeuille".

Maria Bellefeuille  
Illinois Rare Action Network Volunteer State Ambassador