



March 19, 2019

Rep. Will Guzzardi, Chairman  
House Committee on Prescription Drug Affordability  
200-3S Stratton Office Building  
Springfield, IL 62706

**Re: NORD Support for HB 2174**

Dear Chairman Guzzardi and Members of the House Committee on Prescription Drug Affordability,

On behalf of the approximately 1 in 10 individuals living in Illinois with a rare disease, the National Organization for Rare Disorders (NORD) urges the Committee to support HB 2174, a bill to create consumer protections to 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 NORD. Further, NORD acknowledges the immense pressure that payors are under to control costs. Yet failing to support patients today, who are in need of immediate assistance to pay for their prescribed treatment, will have a devastating impact on their health.

Cost is a primary reason why patients decline to fill their prescriptions.<sup>1</sup> Further, non-adherence to prescribed medication is responsible for an estimated 125,000 deaths, ten percent of hospitalizations, and hundreds of billions of dollars in costs to the healthcare system per year.<sup>2,3</sup>

With this in mind, it is vital that Illinois implement consumer protections. Higher cost-sharing tiers within a drug formulary adversely affect patients with rare diseases because most treatments for rare diseases are placed on the so-called "specialty tier" of an insurance plan's drug formulary, which means they are subject to cost-sharing that can be upwards of 50 percent of the actual cost of the medication. This requirement burdens many rare diseases patients and their caregivers with monthly out-of-pocket costs they simply cannot afford.

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<sup>1</sup> *Health Poll: Prescription Drugs*. Report. NPR, Truven Health Analytics. 2017. Accessed February 6, 2019. [http://truvenhealth.com/Portals/0/Assets/TRU\\_18156\\_0617\\_NPR\\_Poll\\_Prescription\\_Drugs\\_FINAL.pdf](http://truvenhealth.com/Portals/0/Assets/TRU_18156_0617_NPR_Poll_Prescription_Drugs_FINAL.pdf).

<sup>2</sup> Viswanathan M, Golin CE, Jones CD, Ashok M, Blalock SJ, Wines RC, et al. Interventions to Improve Adherence to Self-administered Medications for Chronic Diseases in the United States: A Systematic Review. *Ann Intern Med*. ;157:785–795. doi: 10.7326/0003-4819-157-11-201212040-00538

<sup>3</sup> Brody, Jane E. "The Cost of Not Taking Your Medicine." *The New York Times*, April 17, 2017. Accessed February 6, 2019. <https://www.nytimes.com/2017/04/17/well/the-cost-of-not-taking-your-medicine.html?login=email&auth=login-email>.



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 percent of individual and group plans offered in each service area and on each metal tier.
- The 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, such as 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.

Again, NORD urges you to support the important consumer protections outlined in this bill that 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