



December 14, 2020

The Honorable P. Scott Lipps  
Chair, House Health Committee  
Ohio House of Representatives  
77 S. High Street, 13<sup>th</sup> Floor  
Columbus, OH 43215

The Honorable Adam Holmes  
Vice Chair, House Health Committee  
Ohio House of Representatives  
77 S. High St, 13th Floor  
Columbus, OH 43215

The Honorable Janine R. Boyd  
Ranking Member, House Health Committee  
Ohio House of Representatives  
77 S. High Street, 10<sup>th</sup> Floor  
Columbus, OH 43215

Dear Chairman Lipps, Ranking Member Boyd, and Vice Chair Holmes:

On behalf of the 1-in-10 individuals in Ohio with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for the opportunity to submit a letter of support for House Bill 469 (HB 469) to ensure all prescription copayments count towards patient cost-sharing obligations. During this continued time of uncertainty with COVID-19, we ask that you please work to help Ohioans by passing this swiftly out of your committee to help Ohioans.

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. In Ohio, we are proud to be a part of a coalition of more than 50 patient and provider advocacy organizations that are supportive of HB 469. A full list of coalition members in support of HB 469 is included with this letter of support.

A rare disease is defined as any disorder that affects 200,000 or fewer people in the United States. There are over 7,000 such disorders that have been identified, but over 90 percent of them do not have a treatment approved by the Food and Drug Administration.<sup>1</sup> However, even when a treatment exists, access is not always assured. Due to the innovative nature of many of the treatments for rare diseases and the small populations they are intended to treat, these therapies can be expensive. Thankfully, both charitable and manufacturer-based programs exist to help rare disease patients defray the cost.

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<sup>1</sup> Orphan Drugs in the United States; Exclusivity, Pricing and Treated Populations. Report. IQVIA Institute for Human Data Science. 2018. Accessed February 6, 2019. <https://www.iqvia.com/-/media/iqvia/pdfs/institute-reports/orphan-drugs-in-theunited-states-exclusivity-pricing-and-treated-populations.pdf>.



If passed, HB 469 would require cost-sharing amounts paid for prescription drugs by either the insured, or on behalf of the insured by another person, be applied towards a patient's out of pocket expense requirements associated with their health plan. HB 469 would not interfere with health insurance plans' utilization of opportunities to save money by requiring the use of generic medications, as the bill language specifically states, "...this requirement shall not apply with respect to cost-sharing for a drug for which there is a medically generic equivalent."

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. Cost is a primary reason why patients decline to fill their prescriptions.<sup>2</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 health care system per year.<sup>3,4</sup>

It is critical that payments made by patients, or on behalf of patients, apply toward their deductible and yearly maximum out-of-pocket costs. Without applying payments in this manner, patients will be less likely to be able to meet their deductible and, thus, may quickly exhaust any charitable or manufacturer-based assistance they may have by repeatedly paying for the full cost of the drug. If that happens, patients will be left having to pay the bulk of their deductible, as well as the entirety of their copay or coinsurance, despite having already spent enough to meet their deductible. During this already difficult time with COVID-19, patients and their families could be forced to decide between forgoing their critical therapy or facing medical bankruptcy. HB 469 would greatly help rare patients and families in Ohio avoid that tough choice.

Thank you for the opportunity to share our support for HB 469. We appreciate Representative Manchester and Representative West cosponsoring this important legislation and urge your committee to vote in support of the bill. If you have any questions, do not hesitate to contact Anissa Reed with NORD at [AREed@rarediseases.org](mailto:AREed@rarediseases.org).

Sincerely,

*Anissa Reed*

Anissa Reed  
State Policy Manager, Eastern Region  
National Organization for Rare Disorders

Charlene York  
Volunteer State Ambassador  
Ohio Rare Action Network

CC: Members of House Health Committee

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<sup>2</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>3</sup> Viswanathan M, Golin CE, Jones CD, Ashok M, Blalock SJ, Wines RC, et al. Interventions to Improve Adherence to Selfadministered 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>4</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>.