



November 10th, 2020

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

Re: Support for HB 469

Dear Chairman Lipps:

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) urges you to support 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 pass 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.

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, and over 90 percent of them do not have a treatment approved by the Food and Drug Administration.¹ 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.

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.

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

¹ 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>.



decline to fill their prescriptions.² 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.^{3,4}

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 comment on this legislation. We look forward to continuing to work with you on HB 469 to ensure that rare disease patients in Ohio are supported in their daily struggle to afford their medications. If you have any questions, do not hesitate to contact me at hross@rarediseases.org.

Sincerely,

Heidi Ross
Director of State Policy
National Organization for Rare Disorders

Charlene York
Ohio Volunteer State Ambassador
Ohio Rare Action Network

CC: Members of House Health Committee

² 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

³ 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

⁴ 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>.