



July 17, 2019

The Council of State Government
1776 Avenue of the States
Lexington, KY 40511

Dear Council of State Government:

On behalf of the approximately 25 to 30 million individuals in the United States living with a rare disease, the National Organization for Rare Disorders (NORD) urges the Council of State Government (CSG) to include the Virginia Accumulator Adjustment legislation in the volume of legislative ideas at the Share State Legislation meeting. Virginia successfully enacted [Senate Bill 1596](#) in March 2019, to ensure that all payments made toward patients' health care costs count toward their cost-sharing requirements so that they can continue to access their crucially necessary therapies. We believe this would be a good path forward for all states.

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 Even when a treatment exists, however, access is not 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.

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. However, 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.

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>.

Cost is a primary reason why patients 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 healthcare system per year.^{3,4}

With this in mind, 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 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, and could be forced to decide between forgoing their critical therapy or facing medical bankruptcy.

Thank you for the opportunity to comment on this issue. We look forward to working to ensure that rare disease patients in each state are supported in their daily struggle to afford the medications that they need. If you have any questions, do not hesitate to contact me at rsher@rarediseases.org, or 202-545-3970. Thank you again for your consideration.

Sincerely,

/s/

Rachel Sher
Vice President of Policy and Regulatory Affairs

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>.