



March 15, 2019

Governor Jim Justice
State Capitol
1900 Kanawha Blvd. E
Charleston, WV 25305

Re: Support for House Bill 2770

Dear Governor Justice:

On behalf of the approximately 1 in 10 individuals living in West Virginia with a rare disease, the National Organization for Rare Disorders (NORD) urges you to sign House Bill 2770, legislation affirming the ability of patients to apply copay assistance to their cost-sharing requirements.

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 still do not have a treatment approved by the Food and Drug Administration.¹ Even when a treatment does exist, 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. Further, NORD acknowledges the immense pressure that payors are under to control costs. Yet we do not believe that attempts to redress 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, will have a devastating impact on their health.

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}

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-the-united-states-exclusivity-pricing-and-treated-populations.pdf>.

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 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

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>.

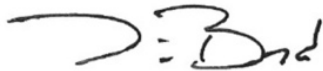
With this in mind, it is critical that payments made by patients, or on behalf of patients, apply toward their deductible and yearly maximum out-of-pocket costs. Without applying payments in this manner, patients will be less likely to meet their deductible and, thus, may quickly exhaust any charitable 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 legislation. Once again, we urge you to sign HB 2770, and we look forward to working with you to ensure that rare disease patients in West Virginia are supported in their daily struggle to afford the medications that they need.

If you have any questions, please contact me at tboyd@rarediseases.org.

Thank you in advance for your consideration.

Sincerely,

A handwritten signature in black ink, appearing to read "T. Boyd". The signature is stylized with a large, sweeping initial "T" and a cursive "Boyd".

Tim Boyd, MPH
Director of State Policy