



March 5, 2020

Senator Matthew Lesser
Co-Chair
Joint Committee on Insurance
Legislative Office Building
Room 3300
Hartford, CT 06106

Representative Sean Scanlon
Co-Chair
Joint Committee on Insurance
Legislative Office Building
Room 2802
Hartford, CT 06106

Re: Support for Senate Bill 336

Dear Co-Chair Lesser and Scanlon:

On behalf of the 1-in-10 individuals in Connecticut with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) urges you to support Senate Bill 336 (SB 336) and pass it swiftly out of your committee.

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.

As you know, SB 336 must apply cost-sharing amounts paid by either the insured or on behalf of the insured by another person for prescription drugs towards a patient’s insurance policy. Cost-sharing includes the coverage limit, copayment, coinsurance, deductible or out of pocket expense requirements associated with an individual’s 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 decline to fill their

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>.



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 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. Patients could be forced to decide between forgoing their critical therapy or facing medical bankruptcy. SB 336 would greatly help rare patients and families in Connecticut avoid that tough choice.

Thank you for the opportunity to comment on this legislation. We look forward to continuing to work with you on SB 336 to ensure that rare disease patients in Connecticut 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. Thank you again for your consideration.

Sincerely,

A handwritten signature in black ink that reads "Heidi Ross".

Heidi Ross
Director of State Policy

A handwritten signature in black ink that reads "Lesley Bennett".

Lesley Bennett
Connecticut Rare Action Network
Volunteer State Ambassador

CC: Joint Committee on Insurance Members

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>.