



February 6, 2018

Tim Boyd, MPH  
Director of State Policy  
tboyd@rarediseases.org

Representative Mitch Greenlick, Chair  
House Health Care Committee  
State Capitol  
900 Court St NE  
Salem, OR 97301

**Re: NORD Support for H 4156**

Dear Chairman Greenlick and Members of the Health Care Committee:

On behalf of the 1-in-10 people in Oregon living with a rare disease, the National Organization for Rare Disorders (NORD) respectfully requests the Health Care Committee to pass H 4156, a bill relating to prescription drug out-of-pocket costs and formulary transparency. This legislation has the potential to benefit many of our organization's members and their patient communities by ensuring that health plans do not place burdensome restrictions on patients that prevent them from obtaining their prescribed medication. With your support for H 4156, you will be benefiting numerous patients suffering from rare disorders in Oregon.

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.

H 4156 will address several issues affecting the rare disease community. First, the bill requires a health insurer to ensure that at least 25 percent of its plans on each metal level utilize a copay-only cost-sharing structure for prescription drugs (with no drug deductible). Within each of these copay-only plans, drug cost sharing must be applied proportionally across all tiers and be reasonably graduated.

The use of higher cost tiers within a drug formulary adversely affects patients with rare diseases because most treatments for rare diseases are placed on the so-called "specialty tier" of an insurance plan drug formulary, which means they are subject to high cost sharing that can be upwards of 50 percent of the actual cost of the drug. This requirement forces many people with rare diseases or their caregivers to pay upwards of \$1,000 per month or go without any medication. As a result, unrestricted out-of-pocket costs limit patient access to medically necessary drugs and biologics as well as target the sickest and most isolated individuals.

Second, the bill enhances transparency for patients about anticipated drug costs within their health plan by requiring insurers to disclose the cost sharing typically paid by an enrollee for each drug on its formulary. This section of the bill also requires plans to disclose whether prior authorization or other restrictions apply to certain drugs.



Finally, H 4156 protects patients by preventing insurers from making drastic changes to their drug formulary in the middle of the plan year. For example, patients will no longer be exposed to mid-year changes in their coinsurance or be subject to new utilization requirements. In addition, insurers cannot drop medications from the covered formulary unless a safety warning has been issued by the Food and Drug Administration (FDA).

Once again, your support for this legislation will be benefiting numerous patients suffering from rare disorders in Oregon. On behalf of our patients, thank you for the opportunity to comment on this legislation. If we can supply additional information, please do not hesitate to let us know.

Sincerely,

A handwritten signature in black ink that reads "Tim Boyd".

Tim Boyd, MPH  
Director of State Policy