



February 25, 2019

House Committee on Health Care
State Capitol
900 Court St NE
Salem, OR 97301

Re: NORD Support for HB 2799

Dear Members of the House Committee on Health Care:

On behalf of the approximately 1 in 10 individuals living in Oregon with a rare disease, the National Organization for Rare Disorders (NORD) urges the Committee to support HB 2799, a bill to create consumer protections that ensure that patients living with chronic and life-threatening conditions have affordable, predictable out-of-pocket costs for the treatments they need.

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.

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% of the actual cost of the medication. This requirement burdens many people with rare diseases or their caregivers with nearly unrestricted monthly out-of-pocket costs they cannot afford. These costs limit patient access to medically necessary drugs, as well as target the sickest and most isolated individuals.

HB 2799 will protect patients by applying the following requirements to state-regulated individual and group insurance plans:

- Each carrier must ensure that a pre-deductible copay is applied to the entire prescription drug benefit in at least 25% of individual and group plans offered in each service area and on each metal tier
- This copay-only benefit design must be reasonably graduated and proportionately related across all tiers of the plan's formulary
- If a carrier offers only one plan in a given metal level within a service area, that one plan must meet the requirements described above



- Requires insurers to annually report changes made during the plan year to their formulary that would adversely impact consumers. These include moving a drug to a higher cost-sharing tier, removing a drug from the formulary or applying additional utilization management controls to a drug during the plan year.

Again, NORD urges your support for the important consumer protections outlined in this bill which will ensure that all Oregonians are able to have affordable, predictable out-of-pocket costs for the treatments they need.

If you have any questions, please contact me at tboyd@rarediseases.org. Thank you in advance for your consideration.

Sincerely,

Tim Boyd, MPH
Director of State Policy