



March 16, 2017

Sen. Lorrie Monnes Anderson, Chair
Senate Health Care Committee
State Capitol
900 Court St NE
Salem, OR 97301

Re: NORD Support for SB 237

Dear Chairwoman Monnes and Members of the Health Care Committee:

The National Organization for Rare Disorders (NORD) respectfully requests the committee to pass SB 237, an act relating to group health benefit plans. This bill has the potential to benefit many of our organization's members and their patient communities by ensuring that health plans do not place burdensome cost sharing restrictions on patients that prevent them from obtaining their prescribed medication.

NORD is the leading voice of the rare disease community dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. Any disease affecting fewer than 200,000 Americans is considered rare. We believe strongly that every patient deserves access to the medical care that is prescribed by their doctor and most likely to give them the best clinical outcomes.

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 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.

SB 237 will protect patients by requiring each health insurance carrier to ensure that at least 25% of its plans on each metal level utilize a copay-only cost-sharing structure for the plan's entire prescription drug benefit, with no drug deductible. Further, in these plans, the cost-sharing assigned to each tier of the formulary must be proportionately related across all tiers and reasonably graduated.

Thank you for the opportunity to comment on this legislation. If we can supply additional information, please do not hesitate to let us know. Jennifer Knapp, NORD's Volunteer State

Ambassador for Oregon, is available to assist you as needed. Jennifer can be reached via email at Jennifer.knapp@rareaction.org

Sincerely,



Peter L. Saltonstall, President and CEO