



June 4, 2014

The Honorable Martin O'Malley
Governor of the State of Maryland
100 State Circle
Annapolis, MD 21401

Dear Governor O'Malley:

On behalf of the 30 million men, women and children in the U.S. affected by the estimated 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for signing Maryland House Bill 761, An Act Concerning Health Insurance – Specialty Drugs, and your continuing support of the rare disease community. This law will limit cost sharing requirements of covered specialty drugs to no more than \$150 per month for up to a 30 day supply of the specialty drug.

As you know, many commercial plans currently utilize specialty tiers for the most expensive drugs, typically biologics. Drugs placed on a specialty tier often require a co-insurance rate between 25-40% of the drug's cost instead of the standard fixed co-payment model used for Tiers I-III. As a result, patients who require drugs that are placed on specialty tiers often must pay thousands of dollars per month to obtain their critical medication.

Specialty tiers also adversely affect patients with rare diseases, as orphan products are often much more expensive than their non-orphan counterparts. For example, a number of orphan drugs cost \$300,000 or more per year. If placed on a Specialty Tier with a co-insurance requirement, these drugs could cost the patient upwards of \$100,000. As a result, not only do specialty tiers limit patient access to medically necessary drugs and biologics, but they also target the sickest and most isolated individuals.

This law will correct this problem in private health insurance plans within the state of Maryland. Not only will this greatly expand access to these critical treatments, but it will also reduce disability and prevent further healthcare costs associated with leaving these conditions untreated.

NORD is a unique federation of patient organizations dedicated to helping people with rare or "orphan" diseases. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. NORD supports a social, political, and financial culture of innovation that supports the basic and translational research necessary to create diagnostic tests and therapies for all rare disorders.

Thank you, Governor O'Malley, for showing your support for the rare disease community by signing this important legislation into law.

Sincerely,

Peter L. Saltonstall
President and CEO