



July 16, 2014

The Honorable Stephan M. Brewer, Chairman
The Senate Ways and Means Committee
Room 212, State House
Boston, MA 02133

The Honorable Jennifer L. Flanagan, Vice Chairwoman
The Senate Ways and Means Committee
Room 208, State House
Boston, MA 02133

Dear Chairman Brewer and Vice Chair Flanagan:

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) urges you to support Senate Bill 2096, An Act Relative to Patient Financial Protection. This bill was introduced to the committee on Senate Ways and Means on April 17, 2014. This law will require plans to establish separate out-of-pocket limits for prescription drugs including specialty drugs. .

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 no out-of-pocket limit, these drugs could cost the patient over \$100,000. As a result, no restrictions on out-of-pocket costs limit patient access to medically necessary drugs and biologics, as well as target the sickest and most isolated individuals.

This law will correct this problem in private health insurance plans within the state of Massachusetts. 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.

NORD and the rare disease community of the Commonwealth of Massachusetts ask that you support the passage of S.2096.

Sincerely,

A handwritten signature in black ink, appearing to read "Peter L. Saltonstall".

Peter L. Saltonstall
President and CEO

CC: Members of the Senate Ways and Means Committee