January 20, 2015

The Honorable Tom Buford, Chairman
Senate Standing Committee on Banking and Insurance
702 Capital Avenue
Annex Room 252
Frankfort, KY 40601

The Honorable Jared Carpenter, Vice Chairman
Senate Standing Committee on Banking and Insurance
702 Capital Avenue
Annex Room 203
Frankfort, KY 40601

Dear Chairman Buford and Vice Chairman Carpenter:

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 Chairman Buford for sponsoring Senate Bill 31, “An Act relating to health benefit plans which include a tiered formulary for prescription drugs”, and urges the Committee to support this vital legislation. This bill will require health insurance plans to limit cost-sharing on specialty medications to $100 per month per prescription, and $200 per month on all specialty medications.

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, unrestricted 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 Commonwealth of Kentucky. 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 Kentucky ask that you support the passage of Senate Bill 31. For questions regarding NORD or our support of this bill, please contact Diane Dorman, Vice President, Public Policy, at ddorman@rarediseases.org, or 202-588-5700, ext. 102.

Sincerely,

Peter L. Saltonstall
President and CEO

CC: Members of the Senate Standing Committee on Banking and Insurance