August 30, 2013

The Honorable David B. McKinley
412 Cannon House Office Building
Washington, DC 20515

Dear Mr. McKinley:

On behalf of the 30 million men, women and children in the U.S. affected by the estimated 7,300 known rare
diseases, the National Organization for Rare Disorders (NORD) thanks you for sponsoring the Patients’ Access to
Treatments Act, H.R. 460, and your continuing support of the rare disease community. This legislation, if enacted,
would limit cost sharing requirements of drugs placed on specialty tiers (Tier IV) to the cost sharing requirements of
non-preferred brand drugs, or Tier III 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 25-33% 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 legislation would correct this problem in ERISA-regulated plans by limiting Tier IV cost sharing requirements
to the specific plan’s Tier III cost sharing requirement. Not only would this greatly expand access to these critical
treatments, but it would 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,
avocacy, 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.

This legislation has NORD’s support and we look forward to working with you to ensure passage of this important
legislation.

Sincerely,

[Signature]
Peter L. Saltonstall
President and CEO