March 2, 2022

The Honorable Bart Rowland
Chair
House Banking & Insurance Committee
702 Capital Ave.
Annex Room 416D
Frankfort, KY 40601

Re: Support for Senate Bill 140

Dear Chair Rowland and Members of the House Banking & Insurance Committee:

On behalf of the 1-in-10 individuals living in Kentucky with one of the approximately 7,000 known rare diseases, the National Organization for Rare Disorders (NORD) thanks you for adding Senate Bill 140 (SB 140) to the House Banking & Insurance Committee’s meeting agenda. SB 140 would ensure that when step therapy is used in Kentucky, it is safe for patients, clinically grounded, and transparent to patients and health care providers.

NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and patient services. NORD believes strongly that all patients should have access to comprehensive, accessible, and affordable health coverage that is best suited to their medical needs.

Step therapy is a tool used by insurers to control costs by requiring a patient to “fail first” on an alternative medication before being granted access to the medication that was originally prescribed by their provider. However, this process of prolonging ineffective treatment and delaying access to the right treatment – especially for patients living with serious or chronic illnesses – can lead to medical setbacks, disease progression, loss of function and even hospitalizations, which may ultimately lead to increased health care costs.

We ask for your support of legislation to allow patients better access to the most appropriate treatment for their condition. SB 140 would accomplish this by ensuring step therapy protocols are based on widely accepted medical and clinical guidelines and updating the clinically justified circumstances for a patient and health care provider to override a step therapy protocol to include when the medicine required under that step therapy protocol:

- Is likely to cause an adverse reaction or physical or mental harm to the patient;
- Has been tried and failed, or another drug in the same pharmacologic class or with the same mechanism of action has been ineffective, had a diminished effect, or caused an adverse reaction for the patient;
- Is not in the best interest of the patient, based on medical necessity; or
- Is different from the medication the patient is currently using successfully to treat their
condition.

It is important to note that SB 140 does not ban the use of step therapy. The common-sense protections that SB 140 will put in place simply ensure that step therapy protocols do not interfere with appropriate care for rare disease patients and families while still enabling health plans to achieve the cost saving benefits of step therapy, when appropriate.

On behalf of the Kentucky rare disease community, we once again thank you for bringing SB 140 before your Committee for consideration and urge its swift passage. For questions regarding NORD or the above testimony please do not hesitate to contact me at AReed@rarediseases.org.

Sincerely,

Annissa Reed
State Policy Manager, Eastern Region
National Organization for Rare Disorders

CC: Members of the House Banking & Insurance Committee